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Responses to Chest Pain: a Qualitative Study

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PhD Thesis

University of Glasgow

**Departments of General Practice and Public Health,
Faculty of Medicine**

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Abstract

Background

Previous research has suggested the existence of socio-economic and gender variations in uptake of hospital cardiology services but it is not known at which stage of the care pathway these variations arise.

Aims and objectives

This thesis aims to address this gap in the literature by exploring the perceptions of and behaviour in response to chest pain of men and women living in two socio-economically contrasting areas of Glasgow. It has 3 objectives: to describe respondents' perceptions of and actions in response to chest pain; to ascertain whether there are differences in perceptions and behaviour associated with socio-economic status or gender; and, to relate any observed differences to the known variations in uptake of cardiology services.

Method

The thesis is based on the qualitative interview stage of a 3-stage study. In-depth interviews were conducted with 30 men and 30 women with chest pain, who were identified using the Rose angina questionnaire. The interviews were recorded and transcribed. Analysis was carried out according to the principles of grounded theory.

Results and conclusions

Respondents' interpretations of chest pain were related to their perceived vulnerability to heart disease and their previous illness experience. Their decisions of whether to present to a general practitioner were influenced by the quality of previous encounters with doctors and by their lay care and self-care. Women generally felt less vulnerable to heart disease than men, and often believed that their health problems were secondary to those of family members. These factors led women to report a reluctance to present with chest pain. Compared with more affluent people, those from the deprived area generally felt more vulnerable to heart disease but the perception that they were to blame for their ill-health often led to reluctance to present with chest pain. Differences in perceptions and behaviour might partly explain gender inequities in access to hospital cardiology services but socio-economic inequities in uptake of services have proved more difficult to explain.

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Preface

In 1996, I was awarded a Wellcome Trust Research Training Fellowship in Health Services Research. The Fellowship provided me with an opportunity to acquire a training in the theory and method of quantitative and qualitative research methods. The study which is reported in this thesis was undertaken concurrently with the Fellowship.

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I would like to thank Professor Graham Watt and Dr Margaret Reid, who provided joint supervision for the study. Professor Watt helped to design the study and oversaw the survey and case-note retrieval stages. He made wise observations and insightful comments throughout the thesis. Dr Reid provided practical and theoretical guidance for the interview study and acted as a source of encouragement and support for the writing of the thesis.

I would like to thank Dr Caroline Morrison, who helped in the study design and supplied me with data from the Glasgow MONICA study, and friends, especially Helen Minnis, Lisa Schwartz, Neil Drummond, Carol Emslie, Kate Hunt and Jane Macnaughton for their advice and moral support.

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Author's declaration

The work presented in this thesis is solely that of the author, Dr Helen Richards.

Chapter 1 Introduction

1.1 Background

Coronary heart disease (CHD) is the leading single cause of death in the United Kingdom (Khaw 1993). Within the UK, the highest rates of CHD mortality are found in Scotland and Northern Ireland, and the lowest rates in the south-east of England (Registrar General 1997). Recent figures show that despite a general decline in CHD mortality rates, Scottish rates are still 15% higher than the UK average (General Registrar for Scotland 1998).

Until the late 1990s, when cancer took the lead, CHD was the commonest cause of death in Scotland. In 1998, it caused the death of 25.3% of men and 20.3% of women [General Register Office for Scotland] (table 1.3). Within Scotland, coronary mortality rates vary widely, with high rates in the west and low rates in the east (Smith, Shewry *et al.* 1990). The Scottish Heart Health Study showed that the standardised mortality ratio (SMR) for men was 121 in Renfrew, a town close to Glasgow, compared with 81 in Edinburgh (Crombie, Smith *et al.* 1986). In addition to this east/west gradient, there are wide local variations with both extremes of CHD mortality occurring in the areas surrounding Glasgow: in 1986, the highest SMR in Scotland of 136 was in Monklands and the lowest, 61, in Eastwood (Crombie, Smith *et al.* 1986).

In the UK, there is a strong positive association between low socio-economic status and high rates of coronary mortality (Marmot, Adelstein *et al.* 1978), (Harding 1995). A positive association is also found when deprivation is measured using the characteristics of geographical areas (Charlton 1996). In Scotland, mortality rates are falling in all groups but at a slower rate in areas of socio-economic deprivation. The two Glasgow populations used in this study were selected to represent the extremes of socio-economic deprivation, and have widely varying coronary mortality rates. In 1996, the standardised mortality ratio for people under the age of 65 in the affluent area used for this study was 57.2, compared to 139.7 in the study's socio-economically deprived area (Greater Glasgow Health Board 1996).

Age-specific mortality rates for CHD are lower in women than men. The Framingham Study, in which 5127 people in the United States, free of clinically manifest CHD at baseline, were examined biennially for 26 years, demonstrated that male coronary mortality rates are equivalent to those of women who are ten years older (Murabito, Evans *et al.* 1993).

CHD results from the narrowing and eventual blockage of the vessels which supply blood to the muscle of the heart (the coronary arteries). The occlusion of these arteries is caused by the formation of fatty deposits (atheromatous plaques) in the internal walls of the arteries and by subsequent addition of blood clots. There are three clinical syndromes of CHD which relate to the extent of the arterial narrowing and the degree to which the blood supply to the heart has been compromised. The first, angina occurs when the oxygen requirements of the heart muscle outstrip the supply, and results from partial blockage of a coronary artery. The commonest form of angina is 'stable angina', whose cardinal clinical feature is pain caused by physical exertion. (Angina which occurs at rest is known as 'unstable angina'.) The second clinical syndrome is myocardial infarction, resulting from complete blockage of a coronary artery and death of the heart muscle supplied by that artery. The third clinical manifestation is sudden death. Patients with stable angina have a 4-6% risk of non-fatal myocardial infarction or death each year (Gandhi, Lampe *et al.* 1995).

The main aims of the management of patients with stable angina are to "*alleviate symptoms and improve life expectancy*" (Scottish Intercollegiate Guidelines Network 1998) (page 22). There are two ways of achieving these aims: the use of drug treatment and coronary revascularisation surgery, the benefits of which are well-established (Mark, Nelson *et al.* 1994). A prerequisite of revascularisation surgery is coronary angiography, which involves the transient filling of the coronary arteries with radio-opaque dye in order to assess their anatomy and patency (Trask, Califf *et al.* 1984). There are two methods of coronary revascularisation: percutaneous transluminal coronary angioplasty (PTCA) and coronary artery bypass graft surgery (CABG). In the former procedure, blood flow is restored to the heart muscle by inflating a balloon at the site of the blockage. CABG involves the replacement of the diseased coronary artery with a healthy vein.

There is strong evidence for socio-economic and gender variations in the uptake of angiography and revascularisation surgery (Payne & Saul 1997), (Black, Langham *et al.* 1995), (MacLeod, Finlayson *et al.* 2000). However, most of the existing research has been descriptive, focussing on variations in rates of uptake of services, rather than analytical. Very little is known about the processes underpinning these rates, such as variations in lay and professional responses to chest pain. Moreover, most research has been carried out using hospital populations, with relative neglect of the earlier stages of the care pathway, such as patients' decisions to consult a general practitioner (GP) and GPs' referral decisions.

1.2 Aims and objectives

The aim of this thesis is to fill part of this gap in the literature, by exploring responses to chest pain amongst men and women living in two socio-economically contrasting areas of Glasgow. The thesis has three objectives: to describe the perceptions of chest pain, and behaviour in response to chest pain of a sample of men and women living in Glasgow; to examine the relationship between respondents' perceptions and behaviour and their socio-economic status and gender and to offer some explanations for gender and socio-economic variations in rates of uptake of cardiology services.

The thesis is based on a 3-stage study using quantitative and qualitative research methods (figure 1.1). First, a large community survey was carried out to collect data about respondents' socio-demographic characteristics and whether or not they had experienced chest pain. Respondents to the survey provided the sampling frame for the other components of the study. Second, data concerning general practice presentation with chest pain were collected from general practice case-notes. Third, in-depth qualitative interviews were carried out with sixty respondents who were asked about their perceptions of and behaviour in response to chest pain. The thesis is mainly based on the qualitative interview study. However, the method of sampling for the survey is reported because it had implications for the recruitment of the interview sample. The findings of the case-note study and the survey are not reported in the main body of the thesis, but their relevance is highlighted where appropriate and the published results are included as appendix 1.

The qualitative study was carried out from an interpretivist perspective, and throughout the thesis I draw on sociological literature. However, I am a general practitioner researcher, not a sociologist, and the thesis is presented not as a sociological study but as a piece of health services research.

1.3 Definitions of terms used in the thesis

1.3.1 Socio-economic status

The traditional basis for assigning social class is occupation, a method which owes its predominance to the inclusion of occupational details on death certificates. However, this method has been criticised in relation to numerator and denominator biases, resulting respectively, from inconsistencies in the recording of occupation on death certificates, and inaccuracies in the census record (Carstairs & Morris 1991a). There are also particular problems associated with the classification of women (Arber 1989) (McDowall 1997) and those who do not have an occupation. Because of these problems, there has been a move towards assigning socio-economic status according to a person's area of residence (area measures), using census data. Area measures have the advantage that they can classify anyone with a residential postcode sector regardless of their employment status. Their main disadvantage is that populations are not homogeneous, so some individuals may be mis-classified.

Frequently used area measures are the Townsend score (Townsend 1987), the Jarman score (Jarman 1983) and DEPCAT (Carstairs & Morris 1991a), all of which take into account male unemployment and social class as well as other variables. In this study, the two sampling frames were based on the residents of two socio-economically contrasting areas of Glasgow. It seemed logical therefore to use an area measure of socio-economic status. DEPCAT was chosen for three reasons: first, it was developed specifically for the analysis of Scottish health data (Carstairs & Morris 1989); second, it has been shown that of the various area measures, DEPCAT and Townsend most closely adhere to the concept of material disadvantage (Morris & Carstairs 1991); and third, it was already available for the study's socio-economically deprived population which was obtained from the Glasgow

MONICA study (Capewell, Morrison *et al.* 1999) (see chapter 5). The aim of DEPCAT is summarised as:

To locate areas (and populations in them) on a dimension which reflects the access people have to material resources which 'permit individuals to play the roles, participate in relationships and follow the customary behaviour which is expected of them by virtue of their membership in society'. (Carman & Britten 1995), quoted in (Carstairs & Morris 1991b)(page 4)

DEPCAT is based on four variables obtained from the census: overcrowding, male unemployment, social class and car ownership. The value of the score ranges from -8.48 (most affluent) to +12.82 (most deprived). For most purposes, including this thesis, these scores are collapsed into seven 'deprivation categories' (DEPCATs), which were designed to retain the discrimination between the categories, rather than to ensure equality of numbers within the categories. The problem of mis-classifying individuals is acknowledged by the authors of DEPCAT, who point out however that there is a strong correlation between household deprivation and the level of deprivation in an area.

Although 'deprivation category' is a convenient way of classifying people, three points about the term require clarification. First, as stated by Carstairs and Morris, the term 'deprivation' is a misnomer when describing the full range of circumstances (from relative deprivation to relative affluence), but that it serves as a "*convenient shorthand for what would otherwise require a more complex label*" (Carstairs & Morris 1991a) (page 4). Second, the term 'deprived' has negative connotations beyond those of material poverty, which may not be acknowledged by the people to whom it is applied. Third, it was observed in this study that people living in areas with the same DEPCAT varied widely in their quality of housing and material wealth.

1.3.2 Gender

A distinction is frequently made by sociologists between a person's biological state (sex) and social identity (gender) (Kessler & McKenna 1978), and there is a continuing discussion in medical sociology about the relevance of biological 'sex' and social 'gender' to health and health-care (Annandale & Hunt 1990). This study draws on the disciplines of

epidemiology, clinical research and medical sociology, which use these terms in different ways. Clinical research tends to use the term 'sex', epidemiology uses 'sex' and 'gender' interchangeably, and in medical sociology the terms are generally used to separate the biological from the social. These issues are discussed in detail elsewhere (Doyal 1998). This study is concerned with the social processes underpinning variations in male and female responses to chest pain. Throughout the thesis, for consistency, the term 'gender' is used to refer to social and biological distinctions between men and women.

1.4 Structure of thesis

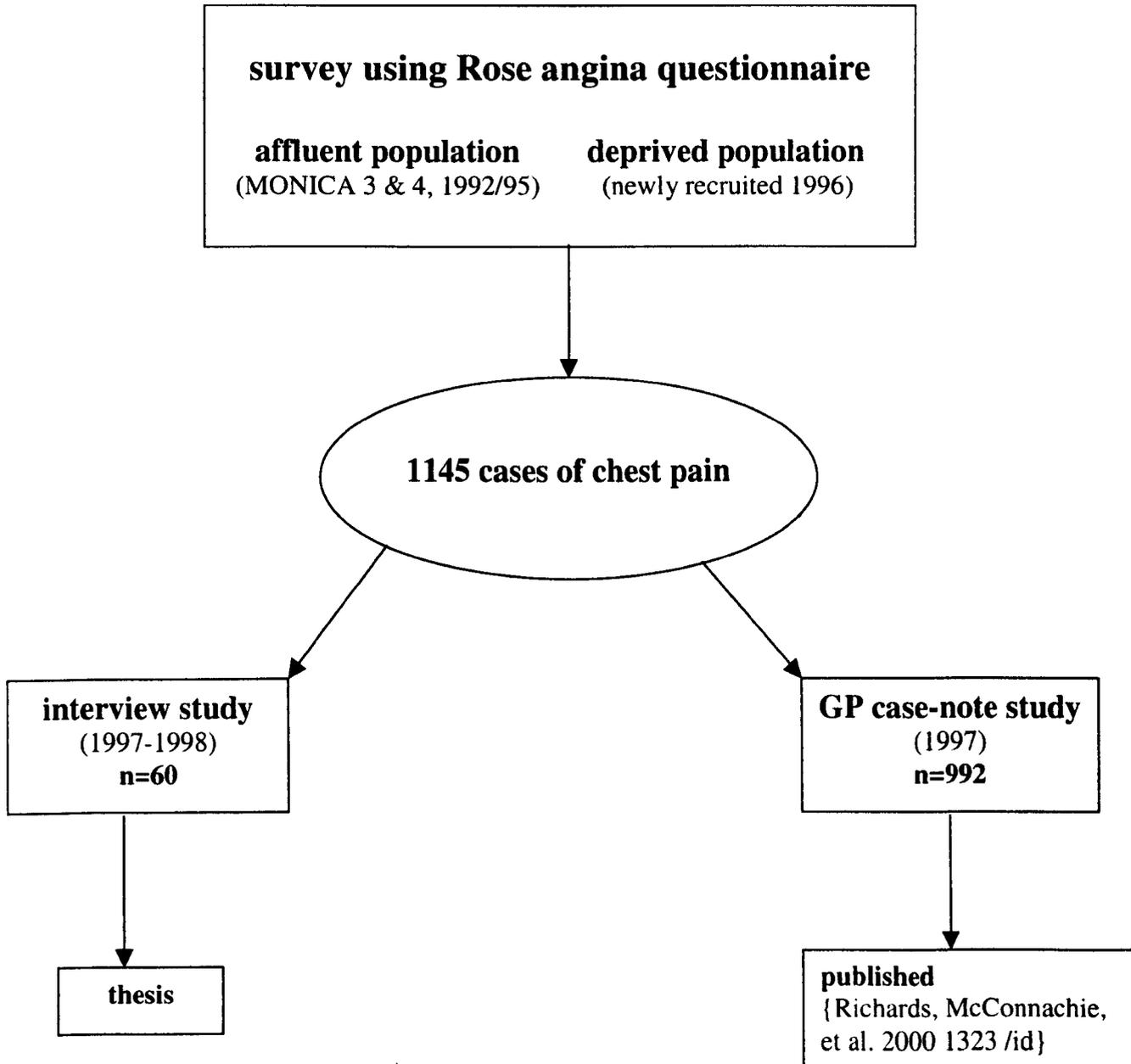
The structure of the thesis is as follows. Chapters 2 to 4 provide a literature review, the large size and scope of which reflect the diversity of the theoretical foundations of the thesis. Chapter 2, which summarises the epidemiological literature, is included in order to provide an epidemiological context for the thesis, and because individuals' perceived risk is likely to be influenced by the prevalence of CHD in their community and socio-demographic group. Chapter 3 reviews the evidence for socio-economic and gender inequities in uptake of cardiology services. Chapter 4 reviews the sociological literature on illness behaviour, and provides the necessary theoretical background for the qualitative analysis.

The study methods are described in chapters 5 and 6. Chapter 5 gives an overview of the study methods, discusses the contribution of the quantitative and qualitative components and describes the methods of the survey. Chapter 6 describes the methods of the interview study.

The interview results are described in chapters 7 to 10. The decision of how best to present the results of the interview study was made after several drafts and a great deal of trial and error. In this final version of the thesis, the qualitative results are presented in four chapters, which have some overlaps but which are essentially independent of each other. It is hoped that this method of presentation will lead to clarity for the reader. The first of these chapters deals with the use of non-medical care strategies, such as lay care and self-care. Chapter 8 describes respondents' perceived vulnerability to heart disease'. Chapter 9

deals with respondents' wider experience of ill-health. The final results chapter (chapter 10) explores the relation between quality of previous experience with health professionals' and subsequent illness behaviour in relation to chest pain. Throughout the four results chapters, verbatim quotations from the interviews are used to illustrate the analytical themes. Pseudonyms are used and some contextual detail has been altered to ensure the anonymity of the respondents. The age, area of residence, marital status and occupation of respondents are provided in chapter 6. Quotations are labelled with the transcript line number so that they can be located.

Chapter 11 summarises and discusses the main findings of the study, addresses some of the methodological issues raised by the study and makes some recommendations for health promotion, health professionals and future research.

Figure 1.1 Outline of the study

Chapter 2 Epidemiology of coronary heart disease

2.1 Geographical and temporal trends in CHD mortality

At the beginning of the twentieth century, the commonest cause of death in the United Kingdom was infectious diseases, and life expectancy at birth was 48 years for men and 51 years for women (Office for National Statistics 1999). Since then, life expectancy has risen to 74 years and 79 years for men and women respectively, and the commonest causes of death are coronary heart disease (CHD) and cancer (Office for National Statistics 1999). In 1998, CHD caused the deaths of 25.3% of Scottish men and 20.3% of Scottish women (table 2.1).

In most westernised countries, including the UK, CHD mortality increased from the beginning of the twentieth century until the mid 1970s. Since the 1970s, a rapid decline in mortality rates has been demonstrated in the United States (Kannel & Thom 1984) and in 18 westernised countries, including England and Wales (Marmot, Booth *et al.* 1981). Routinely collected Scottish data show a 20% reduction in deaths from CHD over the past 10 years (General Registrar for Scotland 1998) (table 2.2) and a similar fall in England and Wales (table 2.3). A study which compared trends in all-cause mortality rates in Glasgow and Edinburgh found that between 1979-83 and 1989-93, coronary mortality fell in both sexes by 16% in Glasgow and 30% in Edinburgh (Watt & Ecob 2000). The authors conclude: "*Reductions in IHD [CHD] mortality provided the largest absolute changes in mortality rates in both sexes and both cities*" (page 333).

Globally, there are wide variations in CHD mortality rates. The MONICA study which monitors trends in CHD in study populations drawn from twenty-one countries has reported that male annual coronary mortality rates varied from 76 per 100,000 of the population in Catalonia, Spain to 365 in Glasgow (Tunstall Pedoe, Kuulasmaa *et al.* 1999). Glasgow had the highest rate of fatal and non-fatal coronary events for women, and for men was second only to North Karelia in Finland. Scottish coronary mortality rates are higher than the UK average (General Registrar for Scotland 1998) and within Scotland, higher mortality rates are found in the west (Smith, Shewry *et al.* 1990).

2.2 Incidence and prevalence of CHD

Although mortality data provide the best indicator of broad temporal and geographical variations, they only provide a partial picture of CHD epidemiology. Some of the most useful insights into the incidence of myocardial infarction and angina have been obtained by the US-based Framingham Study, a prospective cohort study which began in 1948 (Lerner & Kannel 1986) (Kannel & Feinleib 1972). This study measured the incidence of angina, myocardial infarction and sudden death of 2336 men and 2873 women, free of CHD at baseline, for 40 years (Murabito, Evans *et al.* 1993). Angina was defined as, “*recurrent chest discomfort that was brief in duration (≤ 15 minutes), precipitated by exertion or emotion, and relieved by rest or nitro-glycerine*” (page 2549). After 26 years of follow-up, the Framingham Study showed a biennial cardiac event rate of 45.1% in men aged 65-74 and 27.2% in women. Mortality rates in the same age groups were 14% and 5% respectively. For all ages combined, biennial case fatality rates were shown to be higher in men than women (0.32% compared with 0.27%). The Framingham Study also provided data on prognosis after the onset of CHD: after the onset of angina, 1 in 4 men and 1 in 8 women can expect to have a myocardial infarction within 5 years. Within the same period, about 30% of people over 55 years old will die.

Local data on coronary mortality and cardiac event rates have been obtained by the MIDSPAN study (Watt, Hart *et al.* 1995) and the Glasgow MONICA project (Tunstall Pedoe, Morrison *et al.* 1996). The MIDSPAN study took place in Renfrew and Paisley, two towns on the outskirts of Glasgow. It followed up a sample of 7058 men and 8353 women aged 45-64 for more than 15 years, and measured all-cause mortality as well as mortality due to stroke, respiratory disease and CHD. It demonstrated high mortality rates from all causes and found that CHD accounted for 39.3% of male deaths and 29.0% of female deaths (Hawthorne, Watt *et al.* 1995). The Glasgow MONICA study recorded coronary mortality and myocardial infarction in men and women in north Glasgow. In the period from 1985 to 1991, the age-specific annual cardiac event rates in men and women aged 55-64 were 16.7 and 6.5 per 1000 population respectively.

Other large prospective cohort studies which have measured coronary mortality and incidence include the British Regional Heart Study (Shaper, Cook *et al.* 1984) and the

Whitehall Study (Marmot, Rose *et al.* 1978). These studies are limited by their use of all-male samples (Shaper, Cook *et al.* 1984). The Whitehall Study is further limited because it used an occupational sample (Rose, Reid *et al.* 1977).

The incidence of angina is more difficult to measure than either the incidence of myocardial infarction or coronary mortality. First, unlike myocardial infarction, angina usually presents in general practice, a setting less suited to the collection and collation of large standardised data-sets. Second, compared with myocardial infarction or sudden death, the onset of angina is less clearly defined. Third, its clinical diagnosis and definition are more subjective. Angina is the chronic manifestation of CHD and therefore, its prevalence is arguably a more useful measure.

The MIDSPAN study, which used the Rose angina questionnaire (Rose, McCartney *et al.* 1977) to measure community prevalence of angina in people aged 45-64, found a prevalence of 17.7% in men and 16.9% in women. Angina prevalence has also been measured in general practice patient populations, by using routine general practice data (Office for National Statistics 1996), pooled data on prescriptions for anti-angina drugs (Cannon, Connell *et al.* 1988) and practice-specific prescribing data obtained directly from patient records (Bottomley 1997). These studies have the advantage over population studies in that they measure clinical angina. Their disadvantage is that they only identify cases which have been presented to, and diagnosed by a general practitioner. Bottomley (1997) found that when angina prevalence was measured by counting prescriptions for nitrates, the prevalence in the 55-64 age group was 6.2% in men and 4.0% in women. These rates were lower than the rates taken from the general practice disease registers (12.8% in men and 7.5% in women).

2.3 Socio-economic variations in the epidemiology of CHD

A striking aspect of CHD epidemiology is its changing relationship with socio-economic status. In 1931, people in social class I had approximately four times the standardised mortality ratio of people in social class IV (Charlton, Murphy *et al.* 1998). By 1951, the difference in mortality rates between those in social class I and V had narrowed to less than

a twofold difference. And between about 1960 and 1970, the static rates in higher social classes and the continuing increase in semi-skilled and unskilled groups led to a further narrowing of the gap (Rose & Marmot 1981). Since the early 1970s, when total coronary mortality was beginning to fall, rates fell faster in non-manual groups than in manual groups leading to a reversal of the earlier social-class pattern (Marmot & McDowall 1986). These differential rates in the decline of mortality have also occurred in Scotland, leading to a relative excess of coronary mortality in people of lower social class (McLoone & Boddy 1994).

Today, CHD is firmly established as a disease of socio-economic deprivation. This assertion remains true whether deprivation is measured using social class (Marmot, Adelstein *et al.* 1978) (Harding 1995) or the characteristics of a geographical area (Charlton 1996) and equally for mortality, incidence and prevalence of CHD. For example, the male age-standardised rate of treated CHD per 1000 patients in affluent East Anglia in 1991 was 30.1, compared with 44.5 per 1000 in the more deprived north west of England. General practice morbidity data have shown that prevalence of angina varied from 25.8 per 1000 male patients living in areas designated by the Office for National Statistics as 'most prosperous' to 42.0 per 1000 male patients in the more deprived 'coalfields' (Office for National Statistics 1996). For women, there is a similar association between high rates of coronary heart disease and socio-economic deprivation.

The Scottish Heart Health Study which used four measures of social status (level of education, years of education, housing tenure and social class) found that for each of these criteria, people of lower social status had higher angina prevalence (Woodward, Shewry *et al.* 1992). Of the four measures, housing tenure was the best predictor of angina prevalence. The MIDSPAN study demonstrated a positive relationship between angina prevalence and social class. For men the prevalence of angina increased from 11.4% in social class I to 27.8% in social class V. For women, prevalence increased from 15.5% to 19.8% (Hawthorne, Watt *et al.* 1995).

2.4 Gender variations in the epidemiology of CHD

In Scotland, CHD is the cause of death in 25.3% of men and 20.3% of women. A recent report from the Registrar General stated: "*For women, cancer is responsible for a higher proportion of deaths in almost every age group than for men. Conversely, ischaemic heart disease is relatively more important in most age groups of men*" (General Registrar, <http://wood.ccta.gov.uk/grosweb.nsf/pages/library>).

Coronary heart disease accounts for a greater proportion of deaths in men than women and the age-related incidence and mortality rates are higher in men. The Framingham Study demonstrated that although mortality rates increase with age in both sexes, male rates are equivalent to those of women who are ten years older (Murabito, Evans *et al.* 1993). Not only are male coronary mortality rates higher than female rates at all ages, but men on average die ten years younger than women.

As men and women get older, the gender difference in age-related coronary mortality rates decreases and, in the elderly population, rates are very similar (table 2.4). In 1998, Scottish statistics showed that the ratio of male to female mortality rates in the 45-54 year age group was 4.8, compared with just 1.2 in the over 85s (General Register Office for Scotland. <http://wood.ccta.gov.uk/grosweb.nsf/pages/library>, table 6.8). Relative gender differences in CHD mortality are currently decreasing because of increased mortality rates in women (Wenger 1997). The increasing mortality rates in women, combined with the decrease in age-related mortality in elderly populations and women's relative longevity, mean that in the United States, proportionately more women die of CHD than men (Jackson 1994). The female advantage in coronary mortality is countered by the powerful effect of social deprivation. For example, recent figures show that women in the north of England have coronary mortality rates of 324/100,000 compared with 288/100,000 for men in affluent East Anglia (Sharp 1994a).

There are also gender variations in the clinical presentation of CHD and its prognosis. The Framingham Study showed that the commonest clinical expression of CHD in men was myocardial infarction (43%), whereas more than half of the women first experienced

angina (Lerner & Kannel 1986) (Murabito, Evans *et al.* 1993). After the onset of angina, men were at greater risk of myocardial infarction and death than women and after unrecognised myocardial infarction, men were at greater risk of death. However, after recognised myocardial infarction, women's risk of death was greater than that of men. In all of these cases, adjustment was made for age and risk factors (Murabito, Evans *et al.* 1993).

Gender variation in age-related angina prevalence is less pronounced than differences in the incidence of myocardial infarction or coronary mortality. For example, the MIDSPAN study, which identified angina using the Rose angina questionnaire, showed a male prevalence of angina in the 45-64 year age group of 17.7%, compared with 16.9% in women (Hawthorne, Watt *et al.* 1995). The Framingham Study demonstrated that the cumulative prevalence of angina in men and women is very similar. In Framingham men, angina incidence peaked at around the age of 60 years, but in women it continued to increase with age, such that, "*Angina shifts from a predominantly male disease to a predominantly female disease after the age of 75 years*" (Lerner & Kannel 1986) (page 385).

2.5 Explanation of variations

There are three possible types of explanation for the observed temporal, geographical, age-related, socio-economic and gender variations in CHD mortality rates. First, variations may be due to errors or bias in counting; second, they may reflect changes in disease incidence; and third, they may reflect change in case fatality.

2.5.1 Error and bias

Error and bias can arise from variations in diagnostic accuracy and changes in death certification conventions. For example, in 1900, CHD was not included in the disease classification and when, in 1939, the International Classification of Diseases was updated from the 4th to the 5th edition, there was a large shift in diagnosis from 'myocardial disease' to bronchitis (Charlton, Murphy *et al.* 1998). It has been suggested that the wide

socio-economic variation in coronary mortality observed in the 1930s was exaggerated by the mis-classification of myocardial degeneration (a disease of affluence) as coronary heart disease (Martin 1956). The impact of mis-diagnosis and mis-classification of causes of death on mortality statistics can be minimised by using broad categories of disease for analysis. These issues are covered in full elsewhere (Bartley 1996).

Prevalence data may also be subject to error and bias. Officially accepted rates of disease prevalence derived from health service data depend on decisions made along the care pathway, including patients' decisions of whether to seek medical care and doctors' diagnostic decisions. It has been argued, "*Whether or not some untoward event such as exercise-induced chest pain (angina pectoris) ends up as a statistic (a case of x) is as much a function of how providers and the system respond to it as it is the behaviour of the patient and how they react to the event.*" (McKinlay 1996) (page 3). McKinlay suggests that gender variations in these processes may in part explain the widely accepted gender variation in rates of heart disease.

2.5.2 Variations in disease incidence

I have shown that CHD mortality and incidence vary geographically, that they are falling in westernised countries and that they are positively related to male gender and socio-economic deprivation. The most important determinant of these variations is differential levels of risk factors. Risk factors for CHD are well established and include cigarette smoking, high serum cholesterol and hypertension (Sytkowski, Kannel *et al.* 1985), (Shaper, Pocock *et al.* 1985), low levels of fruit and vegetable consumption (Gillman 1996), lack of exercise (Powell 1996), psycho-social stress (Greenwood, Muir *et al.* 1996), early life influences (Robinson 1997) (Fall, Barker *et al.* 1992) and family history (Eaton 1996).

The Framingham Study suggested that a reduction in cardiovascular risk factors was an important contributor to the decline in mortality in cardiovascular disease from the 1950 to the 1970 cohort. The Scottish Heart Health Study (Crombie, Smith *et al.* 1990) has demonstrated that much of the regional variation in CHD mortality is associated with regional clustering of risk factors. Another Scottish study which used data from

epidemiological surveys and routine National Health Service sources compared changes in coronary mortality with changes in treatments and risk factors. It concluded that 51% of the reduction in coronary deaths could be attributed to reductions in measurable risk factors, such as smoking (Capewell, Morrison *et al.* 1999).

Direct evidence that changes in risk factors lead to changes in rates of CHD mortality comes from studies of community-based cardiovascular prevention programmes. Such programmes have been shown to reduce levels of risk factors and lead to a subsequent decline in coronary mortality (Vartiainen, Puska *et al.* 1997). Vartiainen and colleagues showed that mortality fell by 24% in men and 51% in women compared with 12% and 24% in the rest of Finland, which acted as a control population.

There is evidence that much of the socio-economic variation in CHD mortality can be explained by variations in cardiac risk factors. A study which used Scottish Heart Health Study data quantified four of the main coronary risk factors (smoking, serum total cholesterol, blood pressure and obesity) according to social class, housing tenure, education level and employment status. For all risk factors, except cholesterol in men, there was a positive relationship with socio-economic deprivation (Shewry, Smith *et al.* 1992). Smith and colleagues used two Scottish MONICA populations to compare levels of cardiac risk factors, coronary mortality and socio-economic status in north Glasgow and Edinburgh and concluded: "*The socio-economic differences between Edinburgh and North Glasgow largely explain the coronary risk factor differences between the two cities*" (Smith, Shewry *et al.* 1990). Although low socio-economic status has been shown to be associated with high coronary mortality and with high levels of coronary risk factors, there is some evidence from the Whitehall Study that class differences in coronary mortality can not be fully explained by variations in the levels of conventional risk factors (Davey-Smith, Shipley *et al.* 1990).

The female advantage in age-related incidence and prevalence of CHD is widely attributed to the protective effect of endogenous oestrogen in pre-menopausal women. Most of the evidence for this has come from observational studies of premature menopause, using surrogate measures of endogenous oestrogen such as 'age of menopause' (Barrett-Connor & Bush 1991). Further evidence that oestrogen protects women from CHD has been

provided by observational studies, which have shown that women's risk of cardiovascular disease can be lowered by the use of unopposed oral oestrogen (as hormone replacement therapy) (Stampfer & Colditz 1991). This conclusion has been challenged because many of the studies used biased samples of healthy volunteers (Posthuma, Westendorp *et al.* 1994). A recent longitudinal cohort study which used an unbiased sample has, however, demonstrated that risk of CHD was lower in women who had taken combined oestrogen/progesterone hormone replacement therapy (Grodstein, Stampfer *et al.* 1996).

Observational studies have demonstrated that the main cardiac risk factors, such as smoking, hypertension and cholesterol are similarly important in both genders (Croft & Hannaford 1989) (Watt, Hart *et al.* 1995). The MIDSPAN study which compared levels of risk factors (smoking, body mass index, blood pressure cholesterol) with 15-year mortality concluded, "*In general men and women showed similar relationships between risk factor levels and mortality rates.*" (Watt, Hart *et al.* 1995). The main exception to this is diabetes, which is a stronger risk factor in women, possibly because of its interactions with oestrogen (Rich-Edwards, Manson *et al.* 1995).

Although the main cardiac risk factors have a similar relationship with mortality in men and women, their prevalence varies. MIDSPAN showed that the percentage of men aged 60-64 who had never smoked was 15.8% compared with 57.3% of the women. For the younger age group (45-49), the gender difference was much narrower: 18.9% compared with 39.3%. The high prevalence of male smoking at older ages and the narrowing gender difference in younger age groups partly explains the higher age-related mortality rates in men. The increasing prevalence of female smoking may explain the rising age-related incidence of CHD in women (Sharp 1994b).

2.5.3 Variations in case fatality

A decline in coronary case fatality will occur if there is either a reduction in disease severity and/or an improvement in treatment. Most deaths from CHD occur suddenly in previously unsuspected cases, which means that improvements in treatments are likely to be of benefit in just a minority of cases. Also, the recent decline in CHD mortality started after the introduction of coronary care units, and is too large to be explained by the

improvements in cardiac surgery (Heller, Hayward *et al.* 1983). However, there is some evidence that medical and surgical treatments can explain some recent reductions in coronary mortality. In Scotland, a study which combined effectiveness data from meta-analyses with information on CHD patients, found that when using 1975 mortality rates as a standard, there were 6205 fewer deaths than expected. Forty percent of the benefit was attributed to improvements in treatments such as management of hypertension and the use of aspirin for angina (Capewell, Morrison *et al.* 1999). Similarly, a New Zealand study estimated that medical intervention, including resuscitation, beta-blockers and surgery after myocardial infarction could explain 40% of the 126 fewer-than-expected deaths between 1974 and 1981 (Beaglehole 1986). Other studies have shown that case fatality may be reduced by the use of post-myocardial infarction thrombolysis and aspirin (Charlton, Murphy *et al.* 1998) and by improving public response to CHD emergencies (Leslie W.S., Fitzpatrick *et al.* 1996).

Conclusion

This brief review covers the temporal, geographical, socio-economic and gender variations in the epidemiology of CHD. There are six main conclusions: first, CHD is a leading cause of death in men and women in Scotland; second, Scottish coronary mortality rates are higher than the United Kingdom average and within Scotland, higher rates are found in the west; third, Scottish CHD mortality rates are falling; fourth, CHD mortality is positively associated with socio-economic deprivation; fifth, male age-adjusted coronary mortality rates and incidence rates are higher than female rates at all ages, but the cumulative prevalence of CHD is similar in men and women, and finally, the socio-economic variations in coronary mortality rates and incidence are closely associated with variation in the prevalence of cardiac risk factors.

Tables (chapter 2)

Table 2.1 Mortality by frequency of cause for men and women in Scotland (1986, 1991 & 1998)

	% deaths					
	1986		1991		1998	
	men	women	men	women	men	women
all causes	100	100	100	100	100	100
cancer	23.9	21.9	25.9	23.0	26.5	23.5
CHD	32.2	25.1	30.6	24.9	25.3	20.3

General Register Office for Scotland. <http://wood.ccta.gov.uk/grosweb.nsf/pages/library>, table 6.5 (2000)

Table 2.2 Death rates from CHD per 100,000 of the population in Scotland (1950-1998)

year	death rates/100,000	
	men	women
1950	276	203
1960	360	262
1970	407	289
1980	408	304
1990	363	297
1998	287	239

General Register Office for Scotland. <http://wood.ccta.gov.uk/grosweb.nsf/pages/library>, table 6.2 (2000)

Table 2.3 Standardised mortality ratios (SMRs) for CHD in England and Wales (1971-1988)

year	SMR	
	men	women
1971	104	106
1981	100	101
1991	82	91
1998	62	69

Office for National Statistics (standard = average rates for the years 1980-1982)

Table 2.4 Death rates from CHD, by age and gender in Scotland (1998)

age	men	women	ratio
35-44	30	7	4.3
45-54	141	29	4.9
55-64	446	156	2.6
65-74	1160	547	2.1
75-84	2329	1427	1.6
85+	4201	3375	1.2

<http://wood.ccta.gov.uk/grosweb.nsf/pages/library> (2000)

Chapter 3 Variations in uptake of cardiology services

Over the past two decades, evidence has accumulated in the United States and the United Kingdom for socio-economic and gender variations in uptake of cardiology services.

Before discussing this evidence and the explanation for variations, I will outline some of the limitations of the research.

The research is limited in six ways. First, variations in uptake of services must be judged in relation to the level of need for those services in the population. Need for cardiac services has been variously defined as angina prevalence (Payne & Saul 1997), coronary heart disease (CHD) mortality (Black, Langham *et al.* 1995), hospital discharge diagnosis of CHD (Petticrew, Jones *et al.* 1993) and incidence of myocardial infarction (Steingart, Packer *et al.* 1991). Conclusions about inequities vary depending on which definition of need is used. For example, Findlay and colleagues (1994) point out that in Glasgow, if need for coronary angiography is based on mortality rates, there would appear to be an over-investigation of women but if it is defined by angina incidence, there appears to be an under-investigation of women.

Second, studies vary in their definitions of CHD: some use cases of 'angina' identified from general practice case-notes (Spencer, Unwin *et al.* 1995), others use hospital discharge diagnoses (Ayanian & Epstein 1991) (Steingart, Packer *et al.* 1991), and yet others are based on myocardial infarction with raised cardiac enzymes (Krumholz, Douglas *et al.* 1992).

Third, some studies do not control for confounding factors such as age, severity of disease and co-morbidity (Krumholz, Douglas *et al.* 1992). Fourth, studies vary in the populations covered: some are based in one hospital (Krumholz, Douglas *et al.* 1992), others include several hospitals (Clarke, Gray *et al.* 1994), and some are based on community samples (Steingart, Packer *et al.* 1991), leading to variations in their generalisability. Fifth, much of the early work in this area was carried out in the US (Steingart, Packer *et al.* 1991) (Ayanian & Epstein 1991), where there is inadequate insurance cover for women and the

less affluent. Conclusions from these studies are not therefore directly transferable to the UK.

Finally, although uptake of cardiology services depends on events occurring at several stages of a 'care process', which begins with patients' decisions of whether to seek medical care and ends with decisions made in hospitals (Majeed, Chaturvedi *et al.* 1994), most research has concentrated on events occurring in hospital. The earlier stages of the care pathway have been relatively neglected because of the practical difficulty of identifying people before they have become patients, and because the earlier stages of the care pathway involve complex social factors which are not easily explored using survey methods. The remainder of this chapter reviews the evidence for gender and socio-economic variations in uptake of cardiology services and the possible explanations for these variations.

3.1 Socio-economic inequity in uptake of cardiology services

Several recent UK studies have provided evidence for socio-economic inequity in uptake of coronary angiography and coronary artery bypass graft (CABG) surgery. Three cross-sectional ecological studies have suggested that rates of revascularisation vary inversely with socio-economic deprivation. The first of these examined rates of coronary revascularisation in a population of 11.6 million residents of six regions of England and Scotland, and found higher rates in districts which were closer to a regional revascularisation centre. However, that study also found that revascularisation rates varied inversely with need, as measured by coronary mortality rates (Black, Langham *et al.* 1995). The second was based on a single English health authority population and used the "Super Profile"¹ analysis as a measure of deprivation. It also found higher rates of revascularisation close to cardiology centres and demonstrated an inverse relationship between revascularisation rates and levels of deprivation (Manson-Siddle & Robinson 1998). The third of these studies measured angiography and revascularisation rates in one English region. It compared these rates with the characteristics of the region's general practices (including their distance from secondary referral centres and their deprivation

¹ The Super Profile method of classification uses 'lifestyle groups' such as 'affluent achievers' and 'hard-pressed families' to characterise enumeration districts.

scores) and hospital admission rates for CHD for patients registered with the practices. The study found that practices with high deprivation scores had lower angiography and revascularisation rates, and that their patients had to wait longer for these procedures. The authors concluded: *“There may be some under-investigation and/or -treatment of patients with ischaemic [coronary] heart disease from the ‘deprived’ practices”* (Hippisley-Cox & Pringle 2000) (page 1289).

Similar conclusions have been reached by a study which used Rose angina prevalence and CHD mortality as indicators of need (Payne & Saul 1997). Payne and Saul used Townsend scores (Townsend 1987) to measure deprivation and found that both angina prevalence and coronary mortality increased with increasing levels of social deprivation. However, rates of angiography and revascularisation were inversely related to deprivation. The most deprived wards had only half the number of revascularisations per head of population than the more affluent wards, and in affluent wards, 11% of people with symptoms of CHD had coronary angiograms compared with 4% in the poorer wards. The authors concluded: *“The use of interventional cardiology services is not commensurate with need”* (page 257).

There is also some evidence in Scotland for socio-economic inequity in the uptake of cardiology services. Kesson (1995) used routine and non-routine sources to collect data on angiography and revascularisation in the catchment area of one of Glasgow’s main hospitals, and compared these rates with data on coronary mortality. The study demonstrated a statistically significant relative excess of cardiac investigations in people living in the most affluent area compared with those living in the most deprived area. A more recent Scottish study identified all patients admitted with acute myocardial infarction between 1991 and 1993 in Scotland, and measured the 2-year incidence of angiography and CABG (MacLeod, Finlayson *et al.* 2000). It demonstrated that the likelihood of undergoing both of these procedures was lower in areas of socio-economic deprivation.

However, evidence for socio-economic variation in uptake of access to cardiology services is not wholly consistent. An ecological study, which used Townsend score quartiles to measure deprivation and CHD mortality to measure need, found that for women, rates of CABG increased linearly with increasing deprivation, but that in men they were lower than expected in the third deprivation quartile (Ben-Shlomo & Chaturvedi 1995). Similarly, a

study which collected data retrospectively on patients discharged from acute hospitals in Northern Ireland found that there were no differences in rates of invasive investigations between people living in deprived and affluent areas (Kee, Gaffney *et al.* 1993). The authors concluded:

What is required are further studies...preferably involving the collection of detailed data on treatment intensity at each stage of the referral pathway (from patient to general practitioner, to cardiologist to surgeon). Only with these sorts of data might important differences emerge in the treatment of men and women and of materially deprived and affluent groups in our population. (page 1307)

Despite the methodological complexities involved in assessing equity of cardiology services, the existing evidence suggests that there is socio-economic inequity in the uptake of cardiology services. The authors of two of the studies suggest that this inequity represents an example of the “Inverse Care Law”² (Payne & Saul 1997) (Black, Langham *et al.* 1995).

3.2 Gender inequity in uptake of cardiology services

One of the first studies to demonstrate a male excess in the use of cardiac investigations and treatments looked at how the results of nuclear imaging affected management decisions (Tobin, Wassertheil-Smoller *et al.* 1987). That study identified 390 patients who had been referred by hospital physicians for nuclear exercise testing. It found that 40% of the men with abnormal results were referred for catheterisation compared with 4% of the women. After controlling for age and disease severity, the odds ratio for catheterisation for men compared with women was 6.3. Catheterisation is an essential prerequisite to surgery and it was therefore concluded that there were likely to be gender variations in treatment for CHD. Since the early 1980s, a number of similar studies have been carried out in the United States and the United Kingdom, which are summarised briefly below. More detailed summaries are provided elsewhere (Healy 1991),(Laskey 1992),(Findlay 1994).

² The Inverse Care Law states that the availability of good medical care tends to vary inversely with the need for it in the population served (Hart 1971)

Ayanian and Epstein (1991) used hospital discharge data to identify 82,782 cases of CHD and measured rates of angiography, angioplasty and CABG. After controlling for principal diagnosis, secondary diagnoses, age and insurance status, it was found that compared with women, men were more likely to undergo angiography and revascularisation. This difference could not be explained by higher admission rates for women who turned out not to have CHD. A similar study measured rates of angiography and revascularisation in 2473 patients discharged from hospital with myocardial infarction and found no gender difference in rates of referral for angiography (Krumholz, Douglas *et al.* 1992). However in the latter study, of the patients who had angiography, rates of CABG were higher in men. The disparity of the findings of these two studies can be explained by their methodological differences. Whereas Ayanian and Epstein used hospital discharge diagnoses to identify cases of CHD, Krumholz and colleagues used the stricter case definition of 'myocardial infarction with raised level of cardiac enzymes'. Therefore, in the latter study there was less scope for gender to affect referral decisions. Weaknesses of the study by Krumholz and colleagues are that it did not control for hypertension, diabetes and angina, and its generalisability is limited because it was based in a single hospital.

Another study in the United States retrospectively recorded angina severity and rates of catheterisation and revascularisation in 1842 men and 389 women who had been recruited to a therapeutic trial of myocardial infarction (Steingart, Packer *et al.* 1991). The study found no gender difference in angina prevalence but higher rates of functional disability in women. Despite the greater functional disability, women had undergone fewer surgical procedures than men, a gender difference which persisted after adjustment for age, disease severity and co-morbidity. That study also found that once a woman had CHD proved by a positive angiogram or a myocardial infarction, the gender variation in rates of surgery disappeared. The observations that women get equal access to cardiac services only after they have been proven to have CHD has been likened to the fate of Yentl, the heroine of a short story by Isaac Bashevis Singer³, and led Healy (1991) to coin the term 'Yentl syndrome'.

Some researchers have questioned whether gender variations in cardiac services represent over-treatment of men or under-treatment of women (Green & Ruffin 1994). In a

³ In order to attend school and to study the Talmud, Yentl was forced to disguise herself as a boy (Singer 1971).

historical cohort study, 5795 patients were assigned a risk rating for cardiac death, which was determined by a combination of anatomical, physiological and clinical features. For those at high risk of cardiac death (for whom surgery offers the greatest survival benefit), there was no gender difference in surgical referral rates. However, for those at low risk, women were less likely to be referred than men (Bickell, Pieper *et al.* 1992). These results suggest that there might be over-treatment of men. Over-treatment is more likely to occur in the US, where intervention rates are generally higher than in the UK.

All of the above studies were carried out in the United States, but there is also UK evidence for gender inequities in access to cardiology services. For example, a study which investigated angioplasty and CABG rates in 8564 CHD patients discharged from hospital found that after controlling for primary diagnosis, secondary diagnoses, co-morbidity and age, men were more likely to undergo revascularisation than women (Petticrew, Jones *et al.* 1993). A Northern Ireland study which used similar methods showed that angiography rates were higher in men than women and that the gender difference persisted after controlling for different admission rates (Kee, Gaffney *et al.* 1993).

The studies reviewed so far concentrate on events in hospitals. Three important UK studies which address the processes occurring before the patient reaches hospital are detailed below. Clarke and colleagues (1994) measured the route, timing and ward of admission, hospital interventions, treatment and mortality of myocardial infarction patients, and found that women were less likely than men to be admitted to a coronary care unit than men, and were therefore less likely to receive thrombolysis treatment. That study also found that women took longer to get to hospital, possibly because they called a GP instead of going straight to hospital.

Majeed and Cook (1996) used CHD mortality as a proxy for need and made gender comparisons of rates of transfer from primary to secondary care, and cardiac investigation rates. Gender-specific fatality rates were used to indicate disease severity. There were no gender variations in hospital admission rates, but men were more likely to be investigated than women. Once investigated, revascularisation rates were similar in men and women. Two methodological problems of that study weaken its conclusions: first, many cardiology

admissions bypass general practice so, although the study looks at hospital admission rates, it does not address general practitioner referral patterns. Second, CHD mortality, which is higher in men, is used as a proxy for need, and different conclusions may have been drawn if angina prevalence had been used (Findlay, Cunningham *et al.* 1994).

A study which did address GP referral rates by asking 187 people with Rose angina whether they had been referred to hospital for cardiac investigations found that referral rates were higher in men than women (Spencer, Unwin *et al.* 1995). Those findings appear to contradict Majeed's conclusion that male and female hospital admission rates are similar. A possible explanation for this disagreement is that men are more likely than women to bypass the general practitioner.

3.3 Explanations

Three classes of explanation have been suggested for socio-economic and gender variations in uptake of cardiology services: artefact, resulting from limitations and bias in research (see introduction to this chapter); true variations which are clinically justified; and true variations which cannot be justified on clinical grounds (Majeed & Cook 1996).

3.3.1 Clinically justified variations

3.3.1.1 Variations in disease severity and co-morbidity

Clinically justified variations in uptake of cardiology investigations and treatments may arise because of variations between groups in disease severity; levels of co-morbidity; prevalence of risk factors; or in the usefulness of investigations and treatments. For example, Payne and Saul (1997) point out that CHD in deprived populations is more likely to be complicated by risk behaviours such as smoking, and suggest that cardiologists may be reluctant to perform revascularisation procedures on smokers. The studies which have demonstrated socio-economic inequities in uptake of cardiology services generally do not control for co-morbidity or disease severity, and their authors recognise the need for

research which does control for these factors (Black, Langham *et al.* 1995),(Payne & Saul 1997).

Like socio-economic variations, gender inequalities in uptake of cardiology investigations and treatments may be clinically justifiable if there are gender variations in clinical factors such as disease severity and age at presentation, or in the usefulness of the investigations and treatments. This point is made by Laskey (1992).

Gender bias in the management of coronary artery disease can only be present when, after controlling for all possible confounding variables, there remains a significant gender-specific difference in the dependent variable.....it is clear that these end-points must not be interpreted in isolation. (page 870)

All except one (Krumholz, Douglas *et al.* 1992) of the studies demonstrating gender inequalities in uptake of cardiac investigation and treatment controlled for disease severity and co-morbidity, such as diabetes. Therefore it can be concluded that variations in uptake cannot be explained by clinical factors. There is some evidence from UK studies that gender variations may be due to women presenting at older ages (Adams, Jamieson *et al.* 1995),(Hannaford, Kay *et al.* 1996).

3.3.1.2 Variations in diagnostic tests and treatments

The predictive value of a diagnostic test depends on the prevalence of the disease in the population studied. The prevalence of CHD is higher in deprived groups and in men, so it could be argued that higher uptake of diagnostic tests in these groups is justifiable. However, all the evidence relating to socio-economic variations suggests that uptake is higher in more affluent groups. Gender variations are discussed below.

Except in older age groups, CHD prevalence is higher in men than women, which means that diagnostic tests will have higher predictive value in men (Cerqueira 1995), (Taylor & Becker 1990). A study which compared the pre-test probability of CHD (determined by physician assessment and electrocardiogram) with rates of referral for angiography found

that women had lower angiography rates than men, but that the difference could be explained by women's lower pre-test probability of CHD (Mark, Shaw *et al.* 1994).

Even after allowing for gender variations in pre-test probability of CHD, some of the standard diagnostic tests for CHD are less useful in women because of technical constraints (Hsia 1993),(Wenger 1998). For example, exercise electrocardiography, a standard non-invasive diagnostic test, yields a higher number of false positive results in women (67% compared with 8%) and therefore has lower positive predictive value and lower specificity in women (Sketch, Mohiddun *et al.* 1975). Several reasons for the high number of false positives in women have been suggested (Cerqueira 1995) including inadequate duration of exercise, repolarisation abnormalities (Clark, Glasser *et al.* 1988), and the influence of oestrogen (Barrett-Connor, Wilcosky *et al.* 1986).

Myocardial perfusion imaging, a second-line diagnostic investigation which involves injection of a radio-isotope into the blood stream in order to visualise cardiac blood flow, also yields a higher proportion of false positive results in women. In this case, false positives are caused by breast tissue, and can be minimised by ensuring that the radiographs are examined by experienced interpreters (Desmarais, Kaul *et al.* 1993).

Angiography is the diagnostic gold standard for CHD and is equally accurate in men and women. Given the relative unreliability of the other diagnostic tests in women, it has been argued that there should be a lower threshold for angiography in women than in men (Holdright & Fox 1996).

3.3.2 Variations which are not clinically justified

3.3.2.1 Professional responses to chest pain

An Australian study, which compared patients' stated reasons for consulting general practitioners with GPs' assessment and management of the presented problem, found that although women were more likely than men to have a 'cardiovascular' reason for

consulting, they were less likely to have such a condition diagnosed (Sayer & Britt 1996). Similarly, my study of GP case-notes found that men with chest pain were more likely to receive a cardiac diagnosis than women (Richards, McConnachie *et al.* 2000). One possible explanation for the findings of these two studies is that GPs were acting rationally in response to known variations in CHD prevalence. A second possible explanation, suggested by Petticrew and colleagues (1993) is that GPs believe that CHD follows a relatively benign course in women, or that women are less suitable for surgical treatment. Wenger (1990) suggested that the former belief may have stemmed from the Framingham Study, which showed that angina in women was less likely to be followed by a myocardial infarction than in men. She also suggested that the perception that women have poorer outcomes after cardiac surgery may have arisen from early studies of outcomes of coronary surgery (Douglas, King *et al.* 1981). It has since been shown that most of the female excess risk of surgery is attributable to women's older age, smaller size, higher levels of co-morbidity and greater impairment of cardiac function (Hsia 1993) (Khan, Nessim *et al.* 1990) (Weintraub, Wenger *et al.* 1993).

The responses of doctors which have been described above can all be considered rational in the sense that they can be related to gender difference in the epidemiology and clinical course of CHD. There is evidence however that GPs' decisions can be influenced by less tangible factors. Sayer and Britt (1996) suggest that to elucidate the reasons for gender variations in the ways in which GPs deal with men and women, it is necessary to investigate "*general practitioners' beliefs regarding cardiovascular problems*" (page 262). In a USA study, 192 male doctors viewed video-scenarios of patients presenting with chest pain or shortness of breath. The patients varied in their age, race, sex, socio-economic status and health insurance cover. Understandably, the likelihood of a cardiac diagnosis being made increased with increasing age of the patient. However, the study also found that the likelihood of a cardiac diagnosis was higher in those who had health insurance, i.e. the more affluent patients (McKinlay, Potter *et al.* 1996).

In a study of similar design, 44 doctors were randomised and asked to diagnose one of two actress-portrayals of symptoms of CHD, 'histrionic' and 'business-like'. A cardiac cause was suspected by 50% of the doctors watching the business-like portrayal, but in only 13% of those watching the histrionic portrayal (Birdwell, Herbers *et al.* 1991). This study suggests that doctors are influenced by the personality and manner of patients. A further

explanation for gender variations in professional responses to chest pain is that women have been under-represented in cardiovascular research. Despite CHD killing 8,000 women each year and being rated the leading single cause of death of women in the UK (Khaw 1993), most research into the causes, diagnosis and treatment of CHD has concentrated on male populations (Manolio & Harlan 1993) (Healy 1991) (Gurwitz, Nananda *et al.* 1992). Many large observational studies of outcomes and risk factors have not included women (Shaper, Pocock *et al.* 1985) (Rosenman, Brand *et al.* 1978), and the few observational studies which have been on exclusively female populations have focused on female-specific risk factors (Stampfer, Colditz *et al.* 1998) (Croft & Hannaford 1989).

In trials of treatment and prevention, the exclusion of women is even more significant. A review of 214 trials of treatments for acute myocardial infarction found that 4% excluded women completely and that a further 7% excluded women of child-bearing age (Gurwitz, Nananda *et al.* 1992). Although women were not actively excluded from a large proportion of these 214 trials, they only made up 20% of the total randomised subjects. Gurwitz and colleagues (1992) argue that most of the exclusions were made because female subjects with myocardial infarction were too old to be included. A review of 126 US trials found that women made up 38% of the subjects, despite a 49% prevalence of cardiovascular disease in the general population (Harris & Douglas 2000).

Women are also under-represented in many of the larger trials of primary and secondary prevention (Khaw 1993), so for many cardiac risk factors, the strength of the evidence is weaker for women than for men (Rich-Edwards, Manson *et al.* 1995). An American study of risk factor modification (Multiple Risk Factor Intervention Trial Research Group 1990), and a large study of the risk associated with coffee drinking (Grobbee, Rimm *et al.* 1990) both used all-male samples. Trials of cholesterol lowering for the secondary prevention of CHD have included more than 1000 men but only 400 women, and for primary prevention, only 5800 women have participated out of a total of 30,000 (Rich-Edwards, Manson *et al.* 1995). This has led Khaw to make the following observation:

Most research into the causes, prevention, diagnosis and treatment of CHD has been conducted on men - more specifically white middle-aged men. (page 1145)

There are two ways in which the under-representation of women might lead to variations in doctors' responses to chest pain. First, it might reinforce the perception that CHD is a 'male disease' (Griffiths 1995) (Legato, Padus *et al.* 1997). This may in turn lead to differential treatment and referral of men and women by general practitioners. Second, with the current emphasis on evidence-based medicine, the lack of data on CHD in women may lead to gender inequities in the provision of cardiac services:

With the increasing constraints on health services and the emphasis on using only diagnostic procedures and interventions that have been fully evaluated, there may be increasing pressure to exclude population groups who have not been studied from access to particular interventions because of lack of proven benefit. (Khaw 1993) (page 1146)

There are several explanations for the underrepresentation of women in studies of CHD, which have been discussed in detail elsewhere (Khaw 1993) (Rosser 1994). First, the varying hormonal state of women during menstruation and the menopause may lead to difficulties interpreting research findings; second, there is a concern about teratogenicity of drug treatments in women of child-bearing age; third, higher rates of CHD in men give studies greater statistical power; fourth, male study populations are traditionally more accessible, especially when occupational samples are used; and finally, the concentration of CHD research in men has been justified on the basis of their higher rates of premature mortality. It has also been argued that the exclusion of women results from the ways in which money for large trials is allocated and distributed. Rosser (1994) argues that decisions about research priorities and funding in the US are mainly made by white middle- or upper-class men and that "*the research that is undertaken reflects the societal bias toward the powerful*" (page 40).

As well as the studies which have looked specifically at professional responses to chest pain, important insights can be obtained from the more general literature on the ways in which patient gender and socio-economic status can affect doctors' decisions. A study which compared the Jarman deprivation score (Jarman 1983) with general practice referral rates demonstrated higher rates of referral in relatively deprived groups (Chaturvedi & Ben-Shlomo 1995). However, despite the authors arguing that variations in referral rates are likely to reflect differential levels of morbidity, the study did not control for morbidity levels. Another study which compared general practice consultation rates for surgical

conditions such as inguinal herniae, tonsillitis and osteoarthritis with surgical operation rates, found that social deprivation was associated with high consultation rates but low operation rates, suggesting socio-economic inequities in referral to secondary care

A secondary analysis of a national health survey in Australia found that for similar presenting symptoms, women were more likely than men to receive a prescription and to receive investigations than men (Scott, Shiell *et al.* 1996). A qualitative study which explored the process of referral from the point of view of general practitioners in the UK found that among the factors affecting referral decisions were the age, sex and socio-economic status of the patient (Newton, Hayes *et al.* 1991).

3.3.2.2 Lay responses to chest pain

Very little is known about socio-economic variations in perceptions of CHD symptoms. My case-note study showed a higher rate of GP presentation with chest pain amongst people in the socio-economically deprived area compared with those in the affluent area (Richards, McConnachie *et al.* 2000). I argued that this may reflect the general finding that higher rates of consultation are associated with measures of social deprivation, such as unemployment and living in rented accommodation (Carr-Hill, Rice *et al.* 1996), although this association itself has been challenged because variations in consultation rates decrease when morbidity is taken into account (Haynes 1991). Another explanation might be that people in the deprived area feel more vulnerable to CHD because they are aware of its high prevalence in their communities.

My case-note study also demonstrated that men with chest pain were more likely to present than women (odds ratio = 1.53) (Richards, McConnachie *et al.* 2000). This may be because women perceive themselves to be at low risk of CHD or because they adapt to their symptoms rather than presenting. There is some evidence that women perceive CHD as being relatively unimportant (Legato, Padus *et al.* 1997),(Charles & Walters 1994), especially when compared to other health threats such as cancer (Griffiths 1995). Other studies have shown that women rate their risk of CHD as very low (Pilote & Hlatky 1995). Although these studies suggest that CHD is not a high health priority for women, they are based on all-female samples and therefore cannot be used to make comparisons of the

beliefs of men and women. Despite the lack of comparative evidence, the authors of two epidemiological studies have suggested that gender variations in rates of cardiac procedures might reflect a greater preference on the part of women to adapt to the disease rather than choosing to have surgery (Ayanian & Epstein 1991a, Krumholz, Douglas *et al.* 1992).

Conclusion

This chapter has discussed the evidence for gender and socio-economic inequities in uptake of cardiology investigations and treatments, and considered the possible explanations for these inequities. It draws four main conclusions. First, there is strong evidence for gender and socio-economic variations in the uptake of cardiac investigations and treatments. Second, variations in uptake may result from variations in disease severity and co-morbidity or from variations in the usefulness of diagnostic tests and treatments. Such variations may be considered justifiable on clinical grounds. Third, variations in uptake may arise from decisions made by doctors, which are influenced by non-clinical factors, such as perceptions about the value of investigations and treatments and from general ideas about gender and class. Fourth, variations in uptake may arise from decisions made by patients, which are influenced by ideas about 'lay epidemiology' and perceived personal vulnerability to heart disease. The next chapter moves away from variations in the epidemiology and treatment of CHD and reviews the main theoretical underpinnings and important empirical studies of illness behaviour.

Chapter 4 Illness behaviour

This study builds on previous research into illness behaviour. The main theoretical influence is that of interpretivism, but earlier psychological and sociological research has also informed the analysis. This chapter is in two parts. The first part outlines the main theoretical perspectives on illness behaviour, defines interpretivism and explains how it departs from the earlier approaches. More detailed accounts can be found elsewhere (Bury 1997a), (Radley 1994). The second part describes some of the motivations for studying illness behaviour and the empirical research which has influenced this thesis.

4.1 Theoretical perspectives on illness behaviour

4.1.1 Early theoretical perspectives

The first theoretical perspective on illness behaviour was ‘functionalism’ (Parsons 1952), which, in essence, holds that as well as causing biological disruption in the sufferer, illness leads to a disturbance of the sufferer’s social functioning and therefore to disruption to society as a whole. Parsons argued that in order to minimise this social disruption, societies use a system of control, based on the allocation of formal social roles, such as the ‘sick role’. The sick role enables a person with an illness to opt out of normal obligations and responsibilities in a way that is socially acceptable. It carries certain privileges and obligations: on the one hand, the sufferer is excused from normal activities, such as work, and is relieved of the responsibility for the illness; on the other, he or she is obliged to attempt to get well by seeking medical care. Parsons argued that there is a high degree of reciprocity between doctors and patients and that both groups act in a way which preserves social stability. Subsequent sociologists have challenged the assumptions of functionalism, and Bury suggests: “*Parsons’ work has probably been most influential as a foil for the development of alternative views that have been fashioned by subsequent generations of sociologists* “ (Bury 1997b) (page 5).

The three main criticisms of functionalism, which have been discussed at length by Morgan and colleagues (1985a) are: it assumes a universality and predictability of illness behaviour, regardless of social and cultural contexts; it relates mainly to acute illness and has less relevance to chronic health problems; and it generally does not fit with the findings of empirical studies of illness behaviour.

The first challenge to Parsons came in the 1970s (Freidson 1970). Freidson, one of a group of conflict theorists, argued that instead of the reciprocity between patients and doctors suggested by Parsons, there is an inevitable conflict which “*is based on fundamental differences between the biological and social realms in understanding illness*” (Bury 1997a) (page 22). Freidson discarded the functionalist notion of a unitary and homogeneous social structure where participants accept and respond to a single value system. Instead, he argued that there exists a plural system of values, which accounts for the difference in lay definitions of symptoms and illness between groups within a society (Morgan, Calnan *et al.* 1985a) (page 55). Freidson’s work paved the way for a more pluralist and relativist approach to the study of illness behaviour, which took into account lay perspectives and included social and cultural contexts. Both Parsons and Freidson believed that illness is a relatively unproblematic concept, and that where there is a disagreement between lay and medical definitions, the medical definition will prevail. This assumption was also made by Mechanic, who argued:

One of the prime functions of public health programmes is to teach populations to accept, and behave in accordance with, the definitions made by the medical profession. (Mechanic 1968)

In addition to the sociological theories outlined above, important contributions to understanding illness behaviour have been made by psychologists. Psychologists in the 1970s and 1980s emphasised the individual psychological determinants of illness behaviour and largely ignored the influence of cultural and social factors. Psychological models at this time were characterised by an emphasis on predictability and uniformity of behaviour. One of the best known of these models is the Health Belief Model (Rosenstock 1966), which explains illness behaviour according to four psychological variables: ‘perceived susceptibility’, ‘perceived seriousness’, ‘perceived benefits/barriers of taking action’ and ‘cues to action’. The Health Belief Model has been subject to extensive

criticism, and the main criticisms have been summarised by Platt (1997). First, the model's assumption that human beings are "*rational and calculating is partial and therefore inadequate*"; second, it takes the individual as its unit of analysis, neglecting social and cultural contexts; third, it stems from the positivist tradition, tests hypotheses using quantitative data, and is therefore unable to capture lay perspectives of health-related behaviour; and finally, it has low explanatory power.

A second important psychological contribution is the 'Health Locus of Control' (Wallston 1978). This measure is based on a continuous scale but is generally used to divide people into two psychological types: 'internals', who believe that health status is largely under the control of the individual, and 'externals', who believe that health is determined by external forces. The designation of 'internal' and 'external' has been used to explain observed variations in responses to the symptoms of ill-health. The simple dichotomy implied by that model has been called into question by more recent empirical studies (Davison, Frankel *et al.* 1992). Davison and colleagues showed that "*the strong belief that health and illness lie totally inside or outside the realm of the individual influence*" is "*rare*".

Despite the well-founded criticisms of these two psychological models, they have had a major impact on the study of illness behaviour: by 1978, the Health Locus of Control had been used in more than 1000 published studies (Sanders 1982), and the Health Belief Model has been incorporated into several recent studies of illness behaviour in primary care (Campbell & Roland 1996, Van de Kar, Knottnerus *et al.* 1992).

4.1.2 Interpretivism

In the 1970s, sociologists began to challenge the professional dominance of medicine (Illich 1975), and there was a move to an interpretivist⁴ approach to the study of illness behaviour. The interpretivist position differs from the earlier theoretical perspectives outlined above in two important respects. First, instead of accepting the supremacy of medical definitions of illness, interpretivism emphasises the equal status of lay definitions and beliefs. Second, instead of assuming that people react passively and predictably within

a social system, interpretivism stresses that health beliefs and behaviour are shaped by the meanings attached to symptoms by individuals.

The increasing acceptance of interpretivism in sociology is spelled out in Dingwall's paper, 'Illness behaviour: the failure of positivism' (Dingwall 1976), which has been summarised by Morgan and colleagues (Morgan, Calnan *et al.* 1985b) and Calnan (Calnan 1987). Dingwall argued that much previous psychological and sociological research into illness behaviour had been carried out from a scientist⁵ perspective, which involved "*statistical investigation into features of lower class subjects' worlds that the investigator thinks ought to be important*" (page 20). Dingwall wrote:

Medical sociology has worked within a version of the social world derived from medical practitioners and has treated this definition as unproblematic. The integrity of the lay beliefs that sick people use as guides to their actions has been violated and reduced to pathological irrationality. (Dingwall 1976) (page 25)

He presented four main objections to the scientist approach to illness behaviour. First, a quantitative approach may be inadequate for the exploration of social actions; second, scientism is inadequate for understanding the intentions of social actors; third, behaviour is individual and unpredictable, and therefore rigid explanatory models of behaviour are inadequate; and fourth, positivism is absolutist and rejects the idea that there may be different but equally valid ways of seeing the world. At the same time as Dingwall's challenge to positivism, there was a re-examination of the very nature of illness. For example, Field distinguished between medically defined 'disease' and subjective 'illness' (Field 1976), and Helman argued that disease is "something an organ has" and illness is "something a person has" (Helman 1978).

⁴ Interpretivism is a research paradigm, similar to constructivism, which is committed to "*the understanding of the lived experience from the point of view of those who live in it*" (Schwandt 1994) (page 118).

⁵ Scientism carries three basic suppositions: "(i) *The methodological procedure of the natural sciences may be directly adopted by sociology...*(ii) *the goal of the social analyst is to formulate...law-like statements akin to those of the natural sciences...*(iii) *sociology, and knowledge in general, has a purely technical character and is inherently neutral with respect to values and interpretations.*" (Dingwall 1976) (page 15)

The recognition by sociologists of the problematic nature of health and illness and the increased adoption of the interpretivist position paved the way for qualitative research into illness behaviour, which began to uncover the meanings attached to illness by individuals in their own contexts. Dingwall argued: *“If we want to move beyond this [quantification of types of behaviour] to the study of human action, we must adopt a theory and method that take account of the intentions of the actors in their proper context”* (Dingwall 1976) (page 18). This research tradition inspired the method of this study and provided some of the important ideas for the analysis. I have therefore devoted the next section to describing some of the more important examples.

4.2 Empirical research

4.2.1 General research

Much of the earliest research into illness behaviour was carried out in the United States by social anthropologists. Zborowski (1952) explored cultural variations in response to pain by interviewing Americans from four cultural groups. He found that men’s responses to pain were shaped by their cultural contexts and beliefs. For example, Italian men felt at liberty to complain about pain in the medical context, but for Jewish men, although complaining about pain in hospital was also culturally acceptable, their complaints were often an expression of their concerns about their health, rather than an effort to get sympathy. In contrast to both of these groups, Old Americans tended to be less emotional and gave factual accounts of their pain. This was explained on the basis that they were most closely aligned to the medical culture in which the emphasis was on cure rather than on emotional expression.

In a similar study, Zola (1973) studied the ways in which people of Irish and Italian descent communicated their complaints in an outpatient clinic, and like Zborowski, found cultural differences. He also made the more general observation that regardless of cultural background, people often did not present to a doctor at the time when their illness was most severe, but that presentation was often precipitated by social and cultural determinants. These precipitating factors became known as ‘triggers’. Zola identified five

types of trigger: 'interpersonal crises', such as a family argument; 'interference with social relationships', caused for example by embarrassing symptoms; 'sanctioning of symptoms by other people'; 'interference with everyday activities', such as work; and 'recurrence of symptoms'. These two studies have come to be regarded as classics and laid the foundations for future empirical work. Several of the ideas which arose from them, such as the 'sick role', and Zola's 'triggers', have shaped the ways in which health professionals and researchers think about illness behaviour, and have influenced the analysis of the findings of this study.

In the UK in the 1970s, there was an increasing interest in illness behaviour. This has been attributed to a desire amongst health professionals and policy-makers to improve their understanding of illness behaviour, in order to ensure the appropriate use of health services (Bury 1997a). Also, by the 1970s, the idea of the 'illness iceberg' was firmly established. This term was first coined by Last (1963) to describe the observation that the majority of symptoms experienced in the community are never presented to a doctor. The existence of the illness iceberg was unequivocally demonstrated by UK surveys of health and health behaviour (Waldron & Butterfield 1973) (Hannay 1979). Hannay's survey, which was conducted on a sample of patients registered at a Glasgow health centre, found that a quarter of respondents reported at least one symptom which had not been presented to a general practitioner. The 'illness iceberg' was also described in the USA:

Virtually every day of our lives we are subject to a vast array of bodily discomforts...only an infinitesimal amount of these get to a physician. (Zola 1973)(pp 678)

As well as the interest from practitioners and policy-makers, there was an increased interest amongst sociologists in carrying out empirical research into illness behaviour. It was a time when academic interest in illness behaviour and policy concerns coincided:

The interests of sociologists [...] in applying theoretical insights on social behaviour and interaction in the health service field coincided with official and professional concerns with the effects of a period of rapid health service development. (Bury 1997a) (page 28)

Blaxter and Paterson (1982a) collected quantitative data and carried out semi-structured interviews with 58 working-class women, from two generations, living within a similar social and environmental context in Scotland. The central aim of the interview part of Blaxter and Paterson's study was to explore the health, the attitudes to health and illness, and the illness behaviour of two generations of women and their children. The study drew a number of conclusions which are relevant to this thesis. For example, it demonstrated differences between the two generations in their expectations of medicine: the grandmothers often had lower expectations of the scientific claims of medicine, expressed deference to doctors, and had lower expectations of their health. In contrast, the mothers often had high expectations of medical science, were less likely to express feelings of deference and were generally more demanding of the health service. Referring to these intergenerational variations in health attitudes and behaviour, Blaxter and Paterson stress the inadequacy of simple models of illness behaviour and the "*dangers of applying what may well be out-of-date concepts to changing societies*" (page 195). That study made a significant contribution to our understanding of illness behaviour because it was one of the first UK studies which avoided applying preconceived categories or concepts of 'health' and 'disease' and which aimed to capture the perspectives of the respondents. In the analysis, women's words were examined in order to discover their own terminologies, and from the transcripts, the authors derived models of sickness, ideas about disease, and views of health services.

In the 1980s, there was shift in the research focus from illness behaviour to health behaviour: "*Studies of illness behaviour...have now been supplemented with a demand for studies of health behaviour*" (Bury 1997a) (page 36). This shift, which resulted in many studies of lay perceptions of health and illness causation, was underpinned by the decline during the 1960s of acute infectious diseases which had previously been the main health threat in the UK and the increase in chronic, multi-factorial diseases, which were not amenable to simple cures. Also, in the 1980s, there was a shift in the political climate from 'welfarism' to increased individual responsibility, which in relation to health manifested as a growth in the health promotion movement and an increased interest in individual 'lifestyle'⁶.

⁶ The term 'lifestyle' is used in the same way as Davison and colleagues (1992): "*aspects of health-related behaviours and conditions which entail an element of personal action at the individual level*" (page 675).

The UK studies of health behaviour gave rise to several important themes which are discussed further in relevant chapters: first, that lay ideas of health are complex and often do not correlate neatly with medical definitions (Blaxter & Paterson 1982a) (Mullen 1993); second, that ideas about causation, responsibility for, and vulnerability to ill-health are variable and possibly related to individuals' social circumstances (Pill & Stott 1982) (Blaxter 1983); third, that lay people assess their own risk of disease, based on their knowledge of risk factors, and their observations of people in their own social networks: this process has been termed 'lay epidemiology' (Davison, Frankel *et al.* 1992).

In addition to the studies described above, a number of studies have explored illness behaviour specifically in relation to chest pain and heart disease. These studies are described below.

4.2.2 Illness behaviour in response to chest pain and heart disease

CHD is the leading cause of death in the UK, and there has been a considerable amount of research into its epidemiology, treatment and prevention. However, our understanding of illness behaviour in relation to heart disease is under-developed. Morgan and Spanish (1985) state:

Although a vast medical literature exists on the causes and prevention of heart attacks, we know surprisingly little about either the content or the development of the lay person's health beliefs about heart attacks. [Despite the] increasing amount of attention paid to the lay person's general conceptions of illness and its causes, there has been considerably less attention to lay understandings of specific health problems such as heart attacks. (page 401)

One of the earliest studies of illness behaviour in relation to heart disease was carried out by Cowie (1976), who interviewed 27 myocardial infarction patients about their initial responses to symptoms and about their adaptation and return to their normal social roles. The respondents were asked about their initial perceptions of their heart attack, their interpretation of symptoms, and their decision of whether and when to call a GP. That study, which formed the basis of a PhD thesis, provided some useful insights, three of which are particularly relevant to this study. First, chest pain was rarely attributed by the

sufferer or their relatives to a heart attack, and the label 'heart attack' was used only after considering less serious but more common possibilities. Second, respondents often attempted to make sense of their chest pain by comparing it with their previous experiences of ill-health, which were sometimes believed to have caused the chest pain. Third, respondents frequently reported comparing themselves with other patients, in an attempt to make sense of their symptoms and to normalise them. Many respondents sought medical help only when the increasing severity of the chest pain meant that normalisation was no longer possible. These themes are discussed further throughout the thesis. More recent research into responses to chest pain has been driven by two practical concerns. First, since the advent of thrombolysis therapy⁷, there has been a need to understand the factors which cause delay in seeking medical care for acute chest pain (Johnson & King 1995),(Bury, Murphy *et al.* 1992),(Dracup, Moser *et al.* 1995). Second, research into responses to chest pain has arisen from the observation that there are inequities in uptake of cardiology services.

In the USA, Raczynski and colleagues (1994) interviewed 702 black and 1714 white hospital patients with possible CHD, in order to explore racial differences in perceptions and attribution of chest pain. The authors found that white patients reported a greater number of painful symptoms than black patients, but fewer non-painful symptoms. It also found that blacks were less likely than whites to attribute their symptoms to CHD. Several possible explanations for these differences are suggested, including physiological differences between people of different races, variations in culturally determined pain thresholds, and variations in the levels of knowledge about cardiac symptoms. Although reaching no firm conclusions, this study suggests that there may be cultural and ethnic variations in responses to chest pain.

More recently in the UK, Chaturvedi and others (1997) carried out a study which explored ethnic variations in responses to chest pain. They presented hypothetical scenarios of chest pain to 2000 patients registered with London GPs. There were no ethnic differences in the proportion of respondents identifying the pain as cardiac, but Hindus and Sikhs were more likely than Europeans to seek immediate care. No gender or socio-economic variations were found. The authors concluded that differences in patient behaviour could not explain

⁷ Thrombolysis refers to the process of injecting a drug intravenously to disperse blood clots in the coronary arteries and thus limit the damage to the heart caused by a myocardial infarction.

the greater delays experienced by ethnic minority groups in receiving cardiology care, compared with Europeans. However, two features of the method limit the usefulness of the study's conclusions. First, it was based on clinical vignettes which were designed to portray a vague case of chest pain rather than an obvious case of angina or myocardial infarction. This decision was taken because it was assumed that most respondents would seek immediate care in response to an obvious cardiac scenario, and that this uniformity of response would detract from subtle differences between groups. However, it could equally be argued that the vagueness of the chest pain might have led to the concealment of ethnic variations in response to typical cardiac pain. Second, the study was based on a sample whose age ranged from 35 to 55 years (mean age 45), which is relatively young for a cardiac diagnosis, especially amongst women. In addition, although responses to a hypothetical scenario allow comparisons between groups, there is no guarantee that any observed variations reflect reality.

Ruston and colleagues (1998) carried out a qualitative interview study of people admitted to hospital with angina or myocardial infarction, to explore the reasons for delay in seeking help for chest pain. They found that patients' preconceptions of CHD as a sudden dramatic event in which victims collapse and die, were often not borne out by their own experience. Recognition of symptoms by patients as cardiac depended on several factors, such as the typicality of the symptoms, the patients' knowledge of symptoms, their ability to distinguish the chest pain from other symptoms, their perceived personal risk of CHD and their willingness to accept a cardiac label.

An interview study which explored respondents' adjustment following a myocardial infarction (Johnson 1991) identified a number of themes which were similar to those identified in this study. First, patients tended to normalise their symptoms and to attribute their chest pain to a known condition, such as heart-burn; second, ideas about chest pain were closely linked to the respondents' perceived vulnerability to heart disease; third, the decision to seek medical care was influenced by the opinions of lay people, and fourth, heart disease was often associated with guilt and blame.

Most of the studies which have explored lay meanings of chest pain have been carried out on hospital in-patients rather than community-based populations, and have focused on

myocardial infarction rather than angina. This is probably partly because it is simpler to recruit people with myocardial infarction because the diagnosis is clearer and the respondents are 'captive' in hospital. Also, the more dramatic experience of myocardial infarction, compared with angina, may mean that qualitative researchers can elicit richer accounts. There has been relatively little research into lay perceptions of angina, especially in community-based populations.

One of the few primary-care studies designed to explore beliefs about angina was carried out by Gardner and Chapple (1999). That study involved interviews with 16 respondents who had been identified from general practice records as having angina. The authors concluded that angina had different meanings for respondents of different cultural backgrounds. They also suggested that lay meanings are often at variance with the perceptions of general practitioners, and that there are differences between the real-life experience, as observed in primary care, and text-book descriptions of angina. Although Gardner and colleagues make some useful insights into variations in the meaning of angina between different groups, and identified some themes worthy of further exploration, the study is limited by two methodological flaws. First, the study sample was very small. Second, despite claiming to build on epidemiological research which has demonstrated gender, socio-economic, racial and ethnic inequities in the access to cardiac services, the authors do not provide details of the gender, social-class or ethnic backgrounds of their respondents.

4.2.3 Socio-economic and gender variations in illness behaviour

The common assumptions that people of lower socio-economic classes seek medical care more readily than those of higher status and that women seek medical care more readily than men are supported by the Fourth National Morbidity Survey. That survey was based on data collected from 60 volunteer general practices in the UK between September 1991 and August 1992. Data on patterns of service use were compared with a number of socio-economic indicators, including social class, housing tenure and employment status (Carr-Hill, Rice *et al.* 1996). The survey demonstrated higher consultation rates in patients who were classified as unemployed and living in rented accommodation, and that men aged 45-

64 had about three quarters of the general practice consultation rate of women (McCormick, Fleming *et al.* 1995).

However, surprisingly little research has attempted to understand the complexities and reasons underpinning these variations in illness behaviour. Many qualitative studies of illness behaviour have aimed to understand attitudes and behaviour of particular groups and have therefore involved socio-economically homogeneous populations (Cornwell 1984) or have been on exclusively female (Blaxter & Paterson 1982a, McKinlay 1973) or male (Mullen 1993) samples.

Evidence for gender variations in illness behaviour is also limited. Much of the early research was carried out in the USA, and because of the different methods of accessing health services is not likely to be directly relevant to the UK situation. For example, Hibbard and Pope (1983) carried out a study based on a household interview survey completed in 1970/71. The study included 886 women and 762 men who stated that their health was good or excellent. The participants were asked about their perception of medical symptoms and their 'readiness to adopt the sick role'. The main conclusions from this study were that women were more likely to use medical care and that this can be explained by gender variations in "*the way symptoms are perceived, evaluated and acted upon*" (Hibbard & Pope 1986) (page 35). In that study, the observed gender variations in illness behaviour became statistically insignificant after level of morbidity was controlled for. Hibbard and Pope suggested that the gender variations in perceptions stem from three inter-related factors which are all linked to social roles. First, women's roles are more flexible, which allows them more scope for seeking medical care; second, their social roles "*increase the salience of health matters and draw attention to bodily matters*" (page 35); and third, women, through differences in childhood socialisation, may be less inhibited than men about admitting to ill-health.

At this time it was recognised that an understanding of gender variations in illness behaviour was hampered by the lack of studies which controlled for type of medical condition or level of morbidity:

Although the hypotheses about gender differences can be usefully tested for general measures of health (such as number of acute conditions or of prescription drugs in the past month), the best tests will come through studies of specific symptoms and diseases. (Verbrugge 1985a) (page 174)

The few studies which have attempted to control for medical condition and symptom severity have produced varying results. A telephone survey in America found that of respondents reporting a headache within the four weeks leading up to the survey, women were more likely than men to seek medical care (Celentano, Linet *et al.* 1990). In contrast, three other studies have suggested a greater tendency for men to report symptoms. First, a study which compared reports of pain of men and women with similar radiographic evidence of osteoarthritis found that men were more likely to report pain than women (Davis 1981). Second, a study of colonic cancer demonstrated that men were more ready to recognise and seek medical care for symptoms than women (Marshall & Funch 1986). Third, a study of the common cold which compared patient-assessment of symptoms with objective assessments found that compared with women, men were more likely to over-rate their symptoms (Macintyre 1993). Recently, Wyke and colleagues (1998) carried out a study which examined gender variations in the reporting of minor symptoms. Home interviews were conducted with a sample of people taking part in the West of Scotland Twenty-07 study (Ford, Ecob *et al.* 1994), asking respondents whether they had experienced any of 33 symptoms in the last month and whether or not they had presented to a general practitioner. The authors argue that *“these data do not support the most widely suggested explanation for gender differences in consulting, that once symptoms are perceived, women have a higher propensity to consult a general practitioner with the symptom than men”* (page 905).

Several researchers in the UK have highlighted the limitations to our understanding of gender variations in illness behaviour. Wyke and colleagues (1998) point out the lack of evidence that women are more likely to consult for similar conditions, and argue: *“Few studies have examined consulting rates among men and women known to have comparable morbidity”* (page 902). Hunt and Annandale (1999) suggest that our understanding is limited because most studies have taken a quantitative approach, which is ill-suited to interpreting contexts and meanings. Macran and others argue that many studies have ignored social determinants of health, other than gender, such as age, social class and ethnicity (Macran, Clarke *et al.* 1996). The lack of good quality evidence for gender variations in illness behaviour has led to the controversial suggestion that that the

hypothesis that women are more likely to present has taken on “*the character of an urban folk tale*” (Macintyre, Ford *et al.* 1999) (page 91).

Conclusion

The first part of this review has summarised the theoretical developments in the study of illness behaviour and has highlighted the origins and assumptions of the interpretivist perspective adopted in this study, i.e. that health beliefs and behaviour are shaped by the meanings attached to symptoms by individuals, and that lay perspectives are as valid as medical perspectives. The second part has described some of the influential empirical studies, including those which concentrate on chest pain and which provide evidence for gender and socio-economic variations in illness behaviour.

In this review, I have identified several gaps in the current state of knowledge. First, the current political emphasis on health behaviour and illness prevention (rather than illness behaviour) means that there is relatively little recent research of any sort on illness behaviour. Second, few studies have attempted to make gender or socio-economic comparisons of illness behaviour, but have concentrated on eliciting rich data from homogeneous groups. Third, research which was carried out in the 1970s and 1980s has provided some useful general themes but is limited because, with few exceptions, it does not address specific medical conditions, such as CHD. Throughout this thesis, I refer to many of the themes identified by previous theoretical and empirical research and indicate how this study has contributed to our understanding of illness behaviour.

Chapter 5 Overall study design and survey method

5.1 Choice of study design

This thesis reports the findings of the interview stage of a 3-stage study, which also included a survey and a case-note retrieval study. The idea for the original proposal came from several different sources. The MIDSPAN (Hawthorne, Watt *et al.* 1995) and MONICA (Tunstall Pedoe, Kuulasmaa *et al.* 1999) studies have provided evidence for high rates of CHD in Glasgow and the west of Scotland, and there was a growing interest in the Glasgow University Department of General Practice, as in the rest of the UK, about possible inequities in access to cardiology services. I came to the Glasgow Department with an interest in illness behaviour and the ways in which patient decisions can affect access to services. These interests and concerns came together in the first drafts of the study proposal which was put together by a group of four researchers: Professor Graham Watt, Dr Caroline Morrison (Consultant in Public Health Medicine), Dr Sue Ross (Lecturer in Health Services Research) and myself. The proposal was submitted to the Wellcome Trust for consideration for a Training Fellowship, and the Wellcome Committee suggested some changes. At this stage, Dr Margaret Reid agreed to become involved, and with her advice I was able to re-write the proposal, strengthening the qualitative component. The Wellcome Committee approved the revised proposal and agreed to fund a three-year training Training Fellowship in Health Services Research. The study took place between November 1996 and June 2000: a timetable is shown in table 5.1.

The case for combining quantitative and qualitative methods in health services research has been made elsewhere (Barbour 1999) (Black 1994) (Faltermaier 1997) (Freer & Coles 1987). Barbour argues: “*A judicious combination of qualitative and quantitative methods can play a valuable role in health services research*” (Barbour 1999) (page 39). Barbour (1999) summarises the reasons for combining qualitative and quantitative methods as: to “*contribute to different stages of a project*”, to “*compensate for the shortcomings of individual methods*”, and for “*the purpose of triangulation*”. In this study, a mixed-method approach was chosen because it was predicted that the three components would contribute to our understanding of uptake of cardiology services in complementary ways. The aim of the qualitative interview study was to explore responses to chest pain in men

and women from contrasting socio-economic backgrounds. A qualitative approach was adopted for three reasons. First, it allowed a thorough exploration of a topic on which there has been little previous qualitative or quantitative research; second, it facilitated an in-depth and detailed interpretation of the experience of chest pain as reported by the respondents; and third, made it possible to interpret respondents' reported experiences taking into account their social and cultural contexts. Prior to the interview study, an epidemiological survey was carried out. The thesis is based mainly on the interview study, but the survey method is described below because the survey provided the sampling frame for the interview study. The published findings of the survey and case-note review (Richards, McConnachie *et al.* 2000) are included as appendix 1. The method of the interview study is reported in the next chapter.

5.2 The survey

5.2.1 Sampling strategy

The survey had two aims: to provide a sampling frame for the case-note study and the interview study, and to provide a detailed account of the population in order to maximise the generalisability of the qualitative findings. In order to make comparisons based on gender and socio-economic status, it was decided to recruit men and women from two socio-economically contrasting areas of Glasgow. Two contiguous populations were identified within Greater Glasgow Health Board area which had access to the same hospital services. For the socio-economically deprived population (Glasgow north of the Clyde), Rose angina questionnaire data had already been collected as part of the Glasgow MONICA project (Tunstall Pedoe, Kuulasmaa *et al.* 1999). Dr Caroline Morrison, the director of the Glasgow MONICA Project, suggested that the MONICA data could be used in this study. A decision was taken to use the MONICA population as the socio-economically deprived population in this study for three reasons. First, it fulfilled the theoretical requirements of the study (i.e. it consisted of equal numbers of middle-aged men and women from a socially deprived area of the city who had been identified by a community survey as having experienced chest pain). Second, the MONICA method provided a useful methodological 'template' for use in the recruitment of the affluent population, and therefore reduced the need for piloting. Third, by using one population

which had already been identified, it was possible to reduce the time and expense of data collection and therefore to complete a large, mixed-method study within the allotted three years of the research training fellowship.

5.2.2 Recruitment of the study populations

5.2.2.1 The socio-economically deprived population

The Glasgow MONICA study (Tunstall Pedoe, Morrison *et al.* 1996) is part of a world-wide study to MONItor trends in CARdiovascular disease (Bonita 1994), and was carried out in the city of Glasgow, north of the Clyde, which consists mainly of areas of socio-economic deprivation. Each survey of the Glasgow MONICA study aimed to recruit approximately 200 men and 200 women in each of four 10-year age-groups (25-34, 35-44, 45-54 and 55-64). The deprived population used for this study included respondents from the 3rd and 4th Glasgow MONICA surveys, which were recruited in 1992 and 1995 respectively. Details of the MONICA recruitment methods are given elsewhere (Tunstall Pedoe 1988), but aspects relevant to this thesis are summarised below.

In the first stage of recruitment to the Glasgow MONICA study, members of the MONICA team obtained the co-operation of 57 randomly selected general practitioners in Glasgow north of the Clyde. After agreement had been obtained from these GPs, random samples of patients, stratified by gender and age-group, were selected from the practice lists of these GPs. These patients were sent the MONICA questionnaire which included the Rose angina questionnaire. People with chest pain who were identified by the 3rd and 4th Glasgow MONICA surveys made up the socio-economically deprived population for my study. My study excluded people under 45 years because of their relatively low prevalence of coronary heart disease.

5.2.2.2 The affluent population

The affluent population recruited for this study was drawn from an area of Glasgow in which all postcode sectors have Carstairs deprivation scores of 1-3. I aimed to identify a similar number of people with chest pain in this affluent area as had been identified in the deprived area. The required affluent population size was estimated by assuming that the ratio of chest pain prevalence in the two areas was similar to the ratio of the standardised mortality rates for CHD (table 5.2), and by predicting a survey response rate in the affluent area of 75%. It was predicted that in the affluent area, a target population of 5000 people aged 45-64 would be required.

In order to ensure comparability with the socio-economically deprived population, the recruitment methods of the MONICA study were replicated. As in the deprived population, the affluent population was recruited from the lists of GPs, identified using the Community Health Index (Womersley 1996). The affluent area has 24 GPs, which is fewer than the socio-economically deprived area, so it was decided to include all of them. Prior to the survey, a letter was sent to the GPs explaining that a list of their patients had been obtained from the Community Health Index, requesting permission to include their patients in the study, and enclosing a copy of the questionnaire for their perusal. Agreement was obtained from 21 GPs, giving access to 8,211 people aged 45-64 who were resident in the area. Stratified random sampling by gender and four 10-year age-groups was carried out using SPSS for Windows (version 6.13), giving a final sample of 5033 individuals. Table 5.3 shows the distribution of deprivation categories within each population.

5.2.3 Response rates

5.2.3.1 Affluent population

In order to recruit the affluent population, 5033 questionnaires were mailed and of these, 4937 reached the addressee. Of these, 3232 were returned at the end of the third mailing, giving a response rate of 64.2%. Of the 3232 respondents, 161 were excluded because

their true dates of birth fell outside the inclusion criteria. In addition, 196 respondents were excluded because they fulfilled the Rose angina criteria for probable myocardial infarction, and it was judged likely that they would differ significantly with respect to their perceptions of chest pain and their clinical course than those with more straightforward chest pain. After these exclusions, there were 2875 cases for analysis (table 5.4).

5.2.3.2 Deprived population

The response rate for people aged 45-64 in the 3rd and 4th Glasgow MONICA surveys combined was higher than that of the affluent survey, at 70.1% (personal communication, Caroline Morrison) (table 5.5). However, the response rates in the two surveys are not directly comparable because of differences in the ways that they were carried out. Potential respondents in the MONICA study were invited for a health screening examination as well as being asked to complete a questionnaire. It might therefore be expected that the extra effort required of the MONICA respondents would have led to a lower response rate than in my survey. However, the observed higher response rate in the MONICA survey may reflect the relatively high profile of the MONICA study compared with my study, or indicate that a health check can act as an inducement to participating in research.

5.2.4 Questionnaire design

The questionnaire used to survey the affluent population (appendix 2) was based on the Glasgow MONICA questionnaire. Whilst questions about general health and lifestyle were retained to ensure comparability, some shortening was considered necessary. For example, the 'food frequency questionnaire' had been found by others to be over-complex (Caroline Morrison, personal communication) and was replaced by a shorter nutrition section. The two sections which were crucial to the thesis, 'personal details' and the Rose angina questionnaire, were retained unaltered.

Careful consideration of the design and wording of a questionnaire is important to ensure the co-operation of respondents and to maximise the response rate (Sudman & Bradburn 1982) (Stone 1993). In particular, efforts should be made to avoid complex routing within

questions, and ambiguous or double questions. In this study, most of the work of questionnaire design had been done in relation to the Glasgow MONICA questionnaire and it was not necessary to repeat it. However, modification of the content of the questionnaire meant that additional work was required on its layout. The questionnaire was produced as a booklet, as suggested by Sudman (1982), which gave it a professional appearance, made it easy for respondents to turn the pages and prevented pages from getting lost. The questionnaire was given the neutral title “Community Health Study” and to make its origin clear, the Glasgow University crest was printed on the front cover. A note of thanks was included at the end of the questionnaire with a reminder of the return address. Although I acknowledge the general importance of piloting, it was not considered necessary here because all elements of the questionnaire had been used successfully in previous surveys (Tunstall Pedoe, Kuulasmaa *et al.* 1999).

5.2.5 The Rose angina questionnaire

The Rose angina questionnaire, which was developed in 1962, is a screening instrument designed to sort people into those who are more or less likely to have angina (Rose 1962). In the original study, Rose interviewed 36 men with angina about their chest pain, and compared their responses with those of men with non-anginal chest pain. Responses to these open-ended questions formed the basis of the questionnaire. The first question of the Rose angina questionnaire, which is crucial for this study, is: “*Have you ever had pain or discomfort in your chest?*” It is followed by a series of questions about the site of the pain and its relationship to exertion. Pain brought on by exertion is classified as ‘Rose angina’ and pain unrelated to exertion is classified as ‘non-cardiac chest pain’. Rose angina is divided into two grades: grade II, the more severe, is experienced while walking on the flat, and grade I is experienced while walking up-hill or hurrying. A further question, “*Have you ever had a severe pain across the front of your chest lasting for half an hour or more?*”, was later included to identify respondents who have had a probable myocardial infarction. In 1977, a self-administered version of the questionnaire was developed (Rose, McCartney *et al.* 1977), and in 1989, Rose angina was divided into two levels of certainty: ‘definite angina’ when the questionnaire’s subsidiary questions about exertion and site were answered affirmatively, and ‘possible angina’, when at least one subsidiary question was answered negatively (Cook, Shaper *et al.* 1989).

Validation of the Rose angina questionnaire has proved difficult because of the lack of a diagnostic gold standard for angina. The symptoms of angina and its associated structural and functional abnormalities can each occur independently of the others and each aspect is measured using different methods (Hlatky, Mark *et al.* 1989). Abnormalities of structure can be measured by angiography, of function by electrocardiogram or thallium scintigraphy, and of symptoms by clinical history or survey questionnaire. Each method has its own specific purpose and none is inherently superior. Hlatky and colleagues (1989) have argued that the Rose angina questionnaire can only be properly validated by comparing it with other measures of symptoms, such as clinical history, and not with other types of measure, such as angiography. Rose himself acknowledged the problem of validation of the questionnaire:

The validity of these symptomatic diagnoses in absolute terms (that is, the actual numbers of false positive and negative diagnoses) can not be known since no perfect reference test exists. Invasive techniques such as coronary angiography are inappropriate, and could in any case neither prove a false negative nor even wholly disprove a positive diagnosis. The best that can be done is to assess validity indirectly in relation to other measures of disease which are themselves imperfect or incomplete. (Rose, McCartney *et al.* 1977) (page 47)

Despite these fundamental problems, numerous attempts have been made to assess the validity of the Rose angina questionnaire. In a study which compared the Rose angina questionnaire with exercise thallium scintigraphy, it was found that diagnosis of Rose angina had a sensitivity of 26% and a specificity of 79%, and similar overall accuracy in men and women (Bass, Follansbee *et al.* 1989). However the conclusions of that study are weakened because the sample was based on a highly selected population (people who had been referred for thallium testing) and it included just 66 women and 132 men. A study which assessed the repeatability of the Rose angina questionnaire found that repeatability was higher in men, and that having Rose angina on more than one occasion was indicative of a greater severity of disease (Sorlie, Cooper *et al.* 1996).

The Rose angina questionnaire has two fundamental weaknesses. The first is its inadequate validation, discussed above. The second relates to the fact that it was developed using a sample of white, male hospital in-patients, and most validation studies have been carried out on all-male samples (Lampe, Whincup *et al.* 1998). This concentration on a very narrow sector of the population may lead to socio-economic and

gender variations in the way the Rose angina questionnaire is answered. For example, it has been consistently found that despite the known higher prevalence of coronary heart disease in men, rates of Rose angina are similar in both genders with particularly high rates in young women (Hawthorne, Watt *et al.* 1995). This apparent paradox may be because women with Rose angina have exertional chest pain which is non-cardiac in origin or because of gender differences in the reporting of symptoms:

We can only speculate on whether the differences in [the reliability] between sexes and races are due to variability in questionnaire administration, variability in the perception and reporting of pain, or variability in true myocardial ischaemia from one year to the next. (Sorlie, Cooper *et al.* 1996)(page 722)

Despite the limitations of the Rose angina questionnaire, its use was justified in this study because it is a well-established screening tool in cardiovascular epidemiology. Also, in spite of the problems of its validation, there is evidence that the Rose angina questionnaire can predict CHD mortality in both men and women (Hart, Watt *et al.* 1997).

5.2.6 Questionnaire mailing

The questionnaire was sent in three batches, approximately two weeks apart. The original mailing included a covering letter which explained the purpose of the study (appendix 3), assured respondents that answers would be treated confidentially and included a telephone number for queries. In order to maximise the response rate, two reminders, each including a further copy of the questionnaire, were sent at three-week intervals after the original mailing. Replies were logged using Excel for Windows (version 7.0), and data were stored and anonymised in accordance with data protection legislation.

5.2.7 Data entry

The data required for the deprived population, which included the postal addresses and the Rose angina questionnaire responses of people with chest pain, were supplied in ASCII format by the Glasgow MONICA team. Coding and entry of most of the data from the

affluent survey were carried out by a commercial company and also supplied in ASCII format. Occupational details and social class data were coded and entered by myself and the project secretary, to ensure accuracy and consistency.

5.2.8 Data analysis

Table 5.2 shows that although the study populations were recruited from two socio-economically contrasting areas, there was a degree of overlap in deprivation levels between the two populations (10% of the deprived population live in areas of Carstairs deprivation categories 2 and 3). It was therefore decided to merge the data from the two populations and to treat socio-economic deprivation as a 3-level categorical variable. A 3-level categorisation was chosen because it seemed appropriate for an area with wide socio-economic contrasts, and it provided adequate and comparable numbers of cases in each category. This strategy has been successfully used in other studies (McLoone & Boddy 1994) (O'Donnell, McConnachie *et al.* 1999).

Analyses were performed on the prevalence of angina and non-exertional pain. Statistical analyses were performed using logistic regression models fitted by SPSS for Windows (version 6.1.3). The proportions of cases of all chest pain with Rose angina and of Rose angina meeting the more severe grade were modelled with age-group (a 4-level categorical variable: 45-49, 50-54, 55-59, 60-64), and DEPCAT group and gender as independent variables. Significance of the model terms was expressed by the Wald X^2 statistic. Effect estimates were reported as odds ratios with 95% confidence intervals.

The full published results are included as appendix 1. In summary, it was found that compared with the more affluent people, chest pain experienced by people in the deprived area was more likely to be Rose angina and a greater proportion of angina was of the more severe grade. With regard to gender, a greater proportion of chest pain in women was Rose angina but there was no relationship between gender and angina grade.

5.2.9 Ethical considerations

Ethical permission for all parts of the study was obtained from the Greater Glasgow Primary Care Research Ethics Committee, based on a submission of the study proposal. However, a particular ethical issue arose in relation to the use of the Community Health Index as a sampling frame, which warrants further discussion. The Community Health Index is a computer database held at Greater Glasgow Health Board, which includes the names and addresses of all those living in the area and registered with one of the area's GPs. The rules for the use of the Community Health Index as a sampling frame state that all analyses should take place under the supervision of a Public Health consultant, and that permission to use data should be sought from the GPs concerned or the local research ethics committee (Womersley 1996). Despite this survey meeting both conditions, one questionnaire recipient objected to the release of her name and address for research purposes and made a complaint to the Data Protection Registrar. This complaint led me to re-examine the ethical principles and the rules governing the use of the Community Health Index. The opposing ethical principles involved are the protection of the privacy of the individual patient, and the potential benefit to society at large (Knox 1992). Release of data from the Community Health Index is allowed according to section 11, sub-section 11 of the Scottish Home and Health Department's "Confidentiality of Personal Health Information – Code of Practice". However, in a letter to me from the Registrar, it was stated that this is a non-statutory code of practice and subsidiary to the Data Protection Act, which itself does not allow non-consensual disclosure of data for research purposes. The Registrar suggested that future studies should be recruited by contacting the survey sample through the general practices rather than direct mailing to the public. These issues have been debated recently in the medical press (Black 1992) (Markus 1991), particularly in relation to a new European directive (Knox 1992), which, if fully implemented, would severely limit the use of routinely collected data for epidemiological purposes (Warden 1996) (Lyngne 1994). A letter of apology was sent to the woman who made the complaint, and the ethical issues involved have since been closely examined within the Glasgow University Department of General Practice.

Chapter 5 has outlined the structure of the study, provided the rationale behind the choice of study methods and described the survey method. Chapter 6 discusses the method of the interview study.

Tables (chapter 5)

Table 5.1 Timetable of the study

Dates	Stage of study (components not reported in the thesis are shaded)
November 1996 - February 1997	Design and production of the Community Health Study questionnaire
February 1997 - April 1997	Piloting of case-note retrieval forms and case-note retrieval in the deprived population
April 1997 - May 1997	Mailing of the Community Health Study Questionnaire to the affluent population
June 1997 - July 1997	Case-note retrieval in the affluent population
July 1997 - December 1997	Maternity leave
January 1998 - December 1999	Interview study
January 1999 - June 2000	Analysis of data and writing up of study

Table 5.2 Standardised mortality rates (SMRs) for CHD in the two study populations (aged 45-64)

SMR for CHD, based on the 1991 census
(SMR for Greater Glasgow Health Board area = 100)

	deprived population	affluent population	ratio: deprived/affluent
men	134.8	54.4	2.47
women	153.7	65.9	2.33
total	139.7	57.2	2.44

Personal communication, Dr John Womersley, 1997

Table 5.3 DEPCAT distribution within the two study populations (aged 45-64)

population	proportion of the population in each DEPCAT (%)						
	1	2	3	4	5	6	7
deprived	0	6	4	13	10	21	46
affluent	73	7	20	0	0	0	0

Table 5.4 Response rates to survey of the affluent population

	questionnaires sent	questionnaires returned	response rate (%)
men	2485	1446	58.1
women	2548	1769	69.4
total	5033	3215	63.9

(Richards, McConnachie *et al.* 2000)

**Table 5.5 Response rates to the 3rd and 4th Glasgow MONICA surveys
(the deprived population)**

	questionnaires sent	questionnaires returned	response rate (%)
men	1244	852	68.5
women	1289	924	71.1
total	2533	1776	70.1

Personal communication, Dr Caroline Morrison, 1997

Chapter 6 Interview study methods

Chapter 6 sets out the paradigmatic assumptions of the interview study and the rationale for the choice of interviews as the study method. It then describes the data collection and analysis.

6.1 Paradigmatic assumptions and choice of study method

The meaning of the term 'paradigm' is often unclear and ambiguous in the research literature (Atkinson 1995). The definition used here is that of Guba and Lincoln (1994):

A set of basic beliefs (or metaphysics) that deals with ultimates or first principles [...]. The beliefs are basic in the sense that they must be accepted simply on faith. (page 107)

Guba and Lincoln then go on to describe what is meant by a 'research paradigm': "*Inquiry (research) paradigms define for inquirers what it is they are about, and what falls within and outside the limits of legitimate inquiry*" (page 108).

The two contrasting paradigms 'positivism' and 'interpretivism' have already been discussed in relation to the theory of illness behaviour (chapter 4). Positivism assumes the existence of a single 'real' world where the findings of research are considered to be simply true or false. The methodology of positivism is experimental and manipulative and deals with the verification of generalisable hypotheses. Interpretivism, on the other hand, assumes the existence of multiple local realities, which are constructed by 'social actors'. It has been defined by Schwandt (1994) as an approach which is committed to "*the understanding of the lived experience from the point of view of those who live in it*" (page 118), therefore it aims to retain the social context of respondents. It involves careful observations of respondents in their natural settings, and it acknowledges that 'realities' are the result of an interpretative process by the researcher. Although research paradigms are often presented as a spectrum with positivism and interpretivism at the two extremes, it has

been suggested that “*in actual practice of empirical research.. all of us [researchers] are closer to the centre with multiple overlaps*” (Miles & Huberman 1994) (page 5). This study was carried out within an interpretivist paradigm. It set out to discover the meanings attached to the experience of chest pain by the respondents. These meanings were then interpreted, taking into account the social context of the respondents.

Qualitative data can be collected using a variety of methods including participant and non-participant observation, focus groups and in-depth interviews (Britten 1995). Interviews were chosen as the method for this study because I judged that they would be the best way to elicit detailed verbal accounts of respondents’ diverse experiences of chest pain. As pointed out by Marshall and Rossman (1989), interviews also allow immediate clarification of the relevant issues. A single focus group was carried out at the beginning of the study with non-participants in order to define the interview topics, but it was felt that focus groups were unsuited as the main study method because of the personal and sensitive nature of the inquiry. Focus groups are generally used in projects which involve naturally occurring, homogeneous groups, in order to “*capitalise on shared experience*” (Kitzinger 1995) (page 230). Although I made careful observations of the setting and context, observational research methods were not formally employed because they are better suited to situations which allow the direct observation of actions (Mays & Pope 1995), such as the behaviour of people waiting in a casualty department (Schatzman & Strauss 1973).

It is important in a study such as this to consider the nature and status of interview data. Melia (1997) argues that the interview can be seen as “*a presentation of self by the interviewee with the data as a representation that has no further credibility*” or “*as a way of getting a handle on a more complex set of ideas than the ones that the interviewee is ostensibly talking about*”. The assumptions about interview data in this study concur with the latter description: in other words, the data can be taken beyond their face value and, through a process of detailed analysis, be constructed into a more general and meaningful picture.

When making the decision of what method of data collection to use, I took into account the possible influences of my professional background on aspects of the study, such as carrying out the interviews. First, it was necessary for me to decide whether to make my

professional background explicit to the respondents. In making this decision, I took into account Hoddinott's work on attitudes to breast-feeding (Hoddinott & Pill 1999). Hoddinott carried out some of her interviews stating she was a GP, and others stating that she was a 'researcher'. She found that conversation flowed more freely in the interviews in which respondents knew that she was a doctor, and she concluded that in future, she would make her professional background clear. I therefore chose to make my professional background explicit by introducing myself to the respondents as a GP involved in research. I made it clear that I was not currently practising as a doctor and I gave no medical advice. General medical queries were dealt with at the end of the interviews and, if necessary, respondents were referred to their own GPs. Second, I had to adapt my directive clinical interview style to the more open-ended, participant-led style of the qualitative interview. The influence of professional background on qualitative interviewing is discussed further in chapter 11.

6.2 The pilot study

The pilot study was carried out between January 1998 and April 1998. Its objectives were to find out what aspects of chest pain were important to the respondents, to pilot the interview schedule, to test the suitability of the sampling frame and to practise my interview techniques. In order to test out initial ideas for the interview schedule and to generate a list of initial themes, a focus group was held with seven members of the Glasgow University Department of General Practice. Pre-pilot interviews were then conducted with four respondents from the main sampling frame and modifications were made to the interview schedule. For example, the question which was designed to explore respondents' actions in response to general ill-health, "*What action do you take when you feel unwell?*", was found to be too broad and was replaced by a question which included a hypothetical illness example (a cough). After the pre-pilot stage, the first draft of the interview schedule was constructed, taking into account the theoretical considerations of the study. The draft schedule was piloted with a further four respondents and subsequently simplified to nine broad topic areas. The nine areas included: background information; general health; beliefs about health; illness behaviour; history of the chest pain; causes of the pain; emotions about the pain; actions in response to the pain; and perceived risk of heart disease (appendix 4).

6.3 Sampling

Three theoretical considerations influenced the sample design. First, unlike most previous work on access to health services, this thesis was concerned with the perceptions of people who may not have come into contact with health services. This necessitated the identification of a community-based sample, using the Rose angina questionnaire (Rose, McCartney *et al.* 1977) (chapter 5). Second, whereas many studies of illness behaviour have concentrated on exclusively male (Mullen 1993) or female (Blaxter 1983) populations, this thesis aimed to make gender comparisons so required the inclusion of both male and female respondents. Third, in order to make appropriate comparisons, the sample was designed to include respondents from contrasting socio-economic backgrounds.

The sampling frame for the interview study consisted of people identified by the Rose angina questionnaire as having chest pain which worsens on exertion. The socially deprived sample was selected from respondents to the 4th MONICA survey, which took place in 1995, and the affluent sample was selected from respondents to the survey which I completed in 1997 (chapter 5). In order to minimise this temporal difference, respondents to the 4th MONICA survey were re-surveyed in 1997 with the Rose angina questionnaire, and those who responded negatively to this second survey were excluded.

A system of quota sampling was used to obtain fifteen respondents from each of the four sub-groups to ensure adequate and roughly equal representation of men and women from a range of socio-economic circumstances. Individuals were stratified by gender and population (affluent or deprived) and randomly selected using SPSS for Windows (version 6.13). Initially, equal numbers from each sub-group were approached, but to ensure that the final sample included equal numbers from each sub-group, adjustments were made to account for the different response rates. 'Theoretical' sampling (Strauss & Corbin 1998), which involves the modification of the sampling strategy according to the initial findings, was not considered necessary because of the study's clear theoretical basis and the initial inclusion of four sub-groups. The preliminary field-notes and interview transcripts supported this decision.

The classification of people as socio-economically 'deprived' or 'affluent' was based on the characteristics of their area of residence. The use of population indicators to classify individuals meant that there were some cases of apparent mis-classification, i.e. where area status did not tally with social class or housing tenure. In order to provide a more complete picture of the individual respondents, I have provided details of their social class and area deprivation status (tables 6.1-6.4).

Samples of between 20 and 30 respondents are often considered adequate in qualitative studies (Kuzel 1992), because it is often found that larger samples yield little added data. The observation that subsequent interviews fail to provide new themes and concepts is known as saturation. I chose a larger sample size of 60 respondents because this study was based on four pre-determined sub-groups: affluent men, affluent women, deprived men and deprived women, and I wanted to ensure an adequate spread of perceptions in each sub-group. Previous studies based on a number of sub-groups have used samples of similar size (Mullen 1993) (Emslie, Hunt *et al.* 1999).

Potential respondents were sent a letter which thanked them for returning the questionnaire, explained the nature of the interview and stated that they would be contacted by phone to request an interview. For those whose phone number was not initially available, the letter included a reply-paid attachment asking respondents to state whether they were willing to be interviewed, and for their phone number. Those without a phone were asked to return the attachment with possible interview dates or to contact me to arrange an interview. Potential respondents were contacted in batches of approximately 20 so that the interviews could be carried out soon after the initial contact. Where possible, each batch included representatives from each sub-group, so that a range of perceptions would be encountered at all stages of the study.

6.4 Response rates and bias

Table 6.5 shows the response rates in each sub-group. To obtain a quota of 15 respondents from the each of the four sub-groups, it was necessary to write to 114 people. Of these, 6 had recently died and 6 letters were returned unopened. Of the remaining 102 people, 24

did not reply despite a reminder and 18 people declined interview. The overall response rate was therefore 60/102 (59%).

Although the chosen sampling method used does not claim statistical representativeness, the issue of bias is still relevant. Bias can be examined by comparing the characteristics of responders and non-responders. The response rate varied widely between the four groups, from 36.6% for men in the deprived area to 71.2% for the affluent women. The low response rate in the socially deprived area mainly reflected the difficulty experienced in contacting these people by phone. In the socially deprived area, 68% of men were not contactable by phone, compared with 6% of the affluent men. However, once contacted, there was also a higher rate of refusal to take part amongst the deprived groups. Twelve of the 18 people who refused to take part (66.7%) did not give a reason for that decision. Amongst the remaining six respondents, stated reasons for refusal to take part included poor health (in themselves or in family members) (n=4) and work commitments (n=2). All four respondents who gave poor health as a reason for declining interview were from the socio-economically deprived area, and both respondents who cited work commitments were from the affluent area. Although these numbers are very small, they suggest that people from the two areas may have had different reasons for declining interview. In the deprived area, refusal seemed to be associated with poor health and in the affluent area with heavy work commitments. If this speculation is true, the refusal to participate may have de-selected the extremes of socio-economic deprivation and affluence. In the affluent area, the agreement rate was higher in women than men, which may reflect women's greater interest and involvement in health issues and their greater availability.

Although the sampling strategy was designed to select equal numbers of men from two socio-economically contrasting homogeneous groups, the strategy was not entirely successful. First, pockets of affluence in the deprived area and vice versa led to some blatant examples of mis-classification. Second, the classification of some respondents as 'deprived' or 'affluent' did not tally with other indicators of their socio-economic status, such as their social class or housing tenure. In the deprived area, all 15 men and 11 women were in manual occupations. However, in the affluent area, there was more of a mis-match: 10 respondents gave their occupations as manual. This mis-match had a different significance for men and women. Most of the 'manual' men in the affluent area lived in a relatively deprived pocket of social housing, and their socio-economic status was probably

best described by their social class. However, many 'manual' women in the affluent area were married to 'non-manual' men, and their status was probably best described by their area of residence. Third, although respondents were not asked whether they agreed with their designation 'deprived' or 'affluent' (this may well have caused offence), it is likely that many would not.

An alternative approach to sampling by geographic area would have been to classify individuals according to their social class. However, given the well-known problems of assigning social class (chapter 1), I maintain that the use of an area measure of socio-economic status, though imperfect, was justified. Furthermore, the method was at least successful in identifying men and women from a wide range of socio-economic circumstances. In order to give a fuller picture to the reader of the socio-economic status of the respondents, details of occupation and social class are given in addition to whether live in the deprived or the affluent area (tabs 6.1-6.4).

6.5 The interviews

The success of an in-depth interview study depends on obtaining adequate access to participants, effective interview skills of the researcher, and reliable recording of data (Britten 1995). The quality of the data will also be affected by the extent of recall of respondents, and their willingness to divulge information. In order to obtain high quality data from interviews, it is necessary to establish trust and rapport with the respondents by explaining in detail the purpose of the study and uses of the data. In this study, access was facilitated because respondents had already completed a survey questionnaire and therefore had demonstrated that they had some interest in the subject. Access may also have been aided by me stating that I was a doctor. Interviews were arranged at a time convenient to the respondent and all but one were carried out at the respondents' homes. I explained the purpose of the interview and made it clear that transcripts would be seen by a secretary and a research colleague, as well as by myself. I explained that anonymised quotations might be used for illustration when presenting and publishing the research findings. Permission was then sought for tape-recording and transcription of the interviews and was given by all of the respondents.

Field-notes were dictated immediately after each interview, according to the structure suggested by Schatzman and Strauss (1973), who recommended that 4 types of notes be recorded: 'observational notes', to aid the recollection of the interview; 'theoretical notes', about the possible analytical significance of data; 'methodological notes' on the schedule and the general success of the interview; and 'personal notes', which relate to emotional responses to the interviews. Methodological and personal notes allowed me to reflect upon some of the practical problems of carrying out the interviews. Problems included respondents being out when I arrived or being at home but not expecting me and intrusion by others, which sometimes made it difficult for me to concentrate on the interview and sometimes led to problems of audibility for the transcriber. Other seemingly mundane problems such as inappropriate seating positions and uncomfortable temperatures also affected the interviews. The following excerpts from my field-notes illustrate some of these problems:

When I got there, he had completely forgotten about the arrangement and was in a fluster because he and his wife had just got back from one trip and were about to go away again.

The quality of the tape may not be very good because the husband and daughter were talking in the other room and this is bound to be picked up.

The seating position was not ideal. I was sitting next to Andrew on the settee and had to strain to make eye contact. I was sitting next to a heater and I felt very hot and uncomfortable. This is something to bear in mind for the next interviews.

Field-notes also allowed me to monitor the success of the interview schedule and to improve my interview technique. The following excerpts relate to an interview which was carried out early in the study and a later one, respectively.

The main feeling about the interview was that I felt a bit lost and I was concerned about not being able to continue for the expected 60 minutes. I felt that the interview was rambling and I could not think what to ask next. This was partly because his experience of chest pain was fairly non-specific and had not had a major impact on his life.

The interview schedule works quite well. I am beginning to get more confident in the questions.

The tape-recorded interviews were transcribed in full by the research secretary and the transcriptions were checked by myself for accuracy and consistency. It was decided that the dialect of the respondents should be retained, and this was made possible because the research secretary is Glaswegian and familiar with the rich local dialect and vocabulary. The research secretary was closely involved with the project so it was possible to maintain a high and consistent standard of transcription. The transcripts were prepared for entry to QSR NUD*IST software (version 4.0).

6.6 Analysis

Analysis of the data was carried out as a 5-stage process: development of the coding schedule; coding of the data; description of the main themes; linking the themes; and developing explanations for the relationships between themes within a broader theoretical context. The coding schedule was developed using the field-notes and the initial transcripts. In addition, themes were derived from sociological concepts, such as 'lay consultation', and from the theoretical considerations of the study, such as gender variations in CHD. Three transcripts from each sub-group were re-read in detail and all possible themes were recorded, regardless of their immediate apparent relevance. These themes were grouped under headings which formed the basis of the draft coding schedule. This draft was applied to a further six transcripts to ensure that it was broad enough and sufficiently detailed to incorporate all of the data. Some minor changes then resulted in a working draft of the coding schedule, which was then used to code all of the transcripts (appendix 5).

During the coding process, it became evident that some new coding categories were required, and that some were not needed because of overlap of categories. It is important to strike a balance between retaining flexibility of the coding schedule and maintaining consistency of coding for all of the transcripts. After half of the transcripts had been coded, a complete review of all coding categories was carried out, which included recording the extent and consistency of use of each code, and noting examples of

redundancy or overlap. A pragmatic decision was taken to delay adjusting the codes until coding was complete. All eventual adjustments were justified in explanatory memos.

Once coding was complete, it was possible to begin describing the main characteristics of the data. For example, it was evident from reading the transcripts that the level of ill-health varied widely between respondents, and it seemed that 'illness experience' affected responses to chest pain. I therefore decided to follow this 'lead' and to analyse, in detail, the general experience of ill-health in the sample. These data form the basis of chapter 9. Other important themes were 'heart disease as a condition of blame' and 'previous experience of health care'.

The fourth stage in the analytical process was to make links between the main themes. For example, it seemed possible from the early analyses that 'heart disease as a condition of blame' was linked to 'previous experience of health care'. By examining the transcripts in detail, this relationship was confirmed, and it forms a central theme of chapter 10. As well as taking account of the themes which arose from the data, the analysis was explicitly geared to consider the possible influence of socio-economic status and gender on responses to chest pain.

The final stage of the analysis involved the explanation of the relationships between the themes with reference to a broader theoretical framework. For example, to explain the links between 'heart disease as a condition of blame', 'previous experience of health care' and socio-economic status, it was necessary to consider sociological research into the doctor-patient relationship and concepts from health promotion.

Although the process of analysis has been described as having five stages, it was not carried out linearly, but rather as an iterative process which was loosely based on the principles of 'grounded theory' (Strauss & Corbin 1990)⁸. These principles can be

⁸ There is a general lack of agreement about the meaning of grounded theory, which is understandable given its tortuous and controversial historical development. Grounded theory was first 'discovered' in 1967 by Barney Glaser and Anselm Strauss (Glaser & Strauss 1967). Since then, the two founders have published divergent views, (Glaser 1978), (Strauss 1987), (Strauss & Corbin 1990), (Glaser 1992). Melia { 1055 } quotes a letter published by Glaser (Glaser 1978), in which he refers to Strauss's book "Basics of qualitative research" (Strauss & Corbin 1990): "*I request that you pull the book. It distorts and misconceives grounded*

summarised in six main points. First, theory should be derived from data, an approach which is justified because it is more likely than a hypothesis-driven approach to improve understanding of the topic. Second, a researcher should have no pre-conceived theory, just a general overview of the topic, although proponents of grounded theory concede that some studies, such as this, are specifically designed to elaborate and extend existing theory. Third, analysis should involve 'constant comparison', whereby the researcher develops analytical categories from the data and then checks that the meaning and significance of these categories are clear. Fourth, the researcher formulates and makes theoretical links of abstract, or overarching, categories. Fifth, there is an emphasis on flexibility and creativity during the analytical process. Finally, analysis should start at the early stages of a project and all elements of analysis including coding, memo-writing, comparison and theorising should occur concurrently and iteratively.

In practice, grounded theory is dependent on careful coding and the writing of detailed memos throughout the analysis. Three types of codes were suggested by the authors of grounded theory: 'open codes' for recording initial ideas, 'axial codes' for introducing a hierarchical structure into the coding system and 'selective codes', which allow for refinement at later analytical stages (Strauss & Corbin 1990). These roughly coincide with the classes of code used in this analysis. In this study, the data analysis and the writing-up were carried out contemporaneously and iteratively. The importance of the interplay between writing and analysis in qualitative research has been emphasised by Wolcott (Wolcott 1990). I found that writing imposed a structure and logic on the analysis and that it paved the way for subsequent analyses. In addition, writing enabled me to identify new themes and themes which required further development.

The computer software package NUD*IST was used for labelling and sorting data. Its use facilitated rapid and efficient retrieval of data, which in turn allowed a greater range of comparisons to be made both within and across cases. Although it is claimed by the creators of NUD*IST that its design was influenced by grounded theory (Richards &

theory, while engaging in a gross neglect of 90% of its important ideas". It has been suggested that the term is applied, uncritically, as a "bumper sticker" to qualitative studies in order to enhance their respectability.

Richards 1994), I did not find that the programme helped in the intellectual and creative work of the analysis.

6.7 Methodological rigour

Methodological rigour is more problematic for qualitative research than for quantitative research. The terms ‘internal validity’, ‘external validity’, ‘reliability’ and ‘objectivity’ have precise meanings in relation to quantitative research (Polgar & Thomas 1991) but limited applicability to qualitative studies. In this study, I was guided by Lincoln and Guba (1985), who argue that in qualitative studies, these four measures of rigour can be translated respectively into ‘credibility’, ‘transferability’, ‘dependability’ and ‘confirmability’.

Credibility parallels internal validity and is concerned with ensuring that the research topic is adequately identified and described. It is achieved by ensuring that “*an in-depth description showing the complexities of variables and interactions [is] so embedded with data derived from the setting that it cannot help but be valid*” (Marshall & Rossman 1989) (page 145). One method of maximising credibility is by verifying findings with the respondents, so called ‘member-checking’. However, the value of member-checking has been challenged on the basis that the limitations governing the original data will also apply to data collected during the checking exercise (Bloor 1997). In this study, credibility was achieved by providing detailed contextual data such as that relating to respondents’ families, social groups and illness biographies.

Transferability parallels external validity (the extent to which the findings can be applied to other settings). To ensure transferability, the setting of the study must be made clear, so that subsequent researchers can make an informed decision as to whether the framework is applicable to their setting (Marshall & Rossman 1989). Transferability was maximised in this study by combining it with a survey which provided a clear epidemiological context.

Dependability parallels reliability. Its implications are fundamentally different for quantitative and qualitative research. Quantitative studies either assume an unchanging

setting or involve the control of independent variables. In contrast, qualitative studies deliberately incorporate unpredictable elements of social context, which makes replication of findings problematic. In this study, detailed information about the setting and methods has been provided, which means that in theory the study could be replicated. However it is unlikely that the findings and conclusions, which have involved interpretation of the data, would be identical. An established method for checking validity is 'triangulation', which involves combining data collected using more than one method. Triangulation was not carried out in this study, partly for practical reasons and partly because, like Bloor (1997), I question the assumption that triangulation can be considered as a true test of validity. Bloor argued that for any question, there is an optimal research method, so data obtained by other methods will be inferior. He also suggested that different methods yield data which are unlikely to be comparable.

Last, confirmability parallels objectivity, which in this study was maximised in the following ways: first, I used an iterative process of analysis which involved checking and rechecking the data for 'rival hypotheses' and 'negative instances'; second, meticulous field-notes and detailed memos were recorded during all stages of analysis; and third, the study was overseen by an experienced qualitative researcher (Margaret Reid), who critically questioned the developing analysis. Despite these attempts to maximise methodological rigour, this study, like all qualitative research, was inevitably shaped by my preconceptions, theoretical stance and professional background. These issues are considered in the next section.

6.8 Recall of chest pain

The length of time which had elapsed since respondents first experienced chest pain varied from a few months to 20 years, and whereas some respondents had experienced only a few isolated episodes, others complained of ongoing pain. A few respondents no longer had chest pain because they had been successfully treated. Despite the differences in the duration and persistence of chest pain, there were no obvious variations in the clarity of respondents' accounts. Some respondents gave clear accounts of their chest pain after a lapse of many years. For example, Stewart, aged 57, first had chest pain when he was 38 years old:

I've got a very bad memory for things, but I can remember very precisely when I got my first chest pain. Now at that time we were living in Y and I was out for a walk round the village green, and I can remember having to stop because of the chest pain. (365)

The lack of variation in extent of recall may be explained by the ways in which memories are constructed. Memories involve organisation and structuring of experiences, and as part of this process, information is selected and discarded (Thompson 1978). Psychological experiments have shown that "*the initial discarding is by far the most drastic and violent*" (page 111), and that after an initial process of reorganisation, the memory remains relatively constant, even after 30 or 40 years. Experiments in oral history have shown that more important than the time-lapse between the event and the interview is the significance of the event to the individual. In this study, poor recall of chest pain was often related to a lack of perceived seriousness of the pain, rather than to a long time-lapse between the pain and the interview. For example, James implied that his experience was trivial, and then said: "*I would find it difficult to put a date on it, but I would say I've been conscious of it, probably on and off, for many years*" (91). Respondents used two techniques to aid their recall: first, they dated their chest pain with reference to memorable life-events, such as holidays or birthdays. For example, Sandy said: "*I can tell you exactly when it was 'cause it was my wife's birthday [date], the year's a bit more difficult*" (342). Second, some respondents linked the onset of their chest pain to their activity at its onset. Regardless of the completeness of recall, it has been argued that accounts of chest pain are edited versions of the experience which have been influenced by subsequent events, knowledge and experience (Cowie 1976). Cowie termed this process 'retrospective reconstruction', and recognised that it complicates the researcher's analytic task:

It is impossible to separate the knowledge with which the patient operated at the time of the [heart] attack from that used to provide a *post-facto* definition of the situation for himself and for the researcher during the interview. The researcher is not simply faced with the problem of the degree to which the patient can recall events, but the more complex process of rewriting the events. (page 300)

Even though the duration of chest pain and the time-lapse between the chest pain and the interview were not likely to have a great influence on respondents' accounts, these variations were minimised by asking the respondents to focus on their first episode of chest pain.

6.9 Doctor as researcher

Many qualitative researchers have provided autobiographical accounts of aspects of their research experience to illustrate issues that have a general relevance. For example, Oakley (1981) described her experience of interviewing women about childbirth to highlight the power relations in the interview situation and to argue for a feminist methodology, and Boman and Jevne (2000) give a personal account of their experience of dealing with some ethical problems of qualitative research. Here, I examine the issue of the influence of my medical background on this study.

Qualitative methods are particularly suited to research in primary care because, like primary care, they are concerned with subjective meanings of the experience of illness, and they are interested in individuals who are situated within their family, social and cultural contexts (Murphy & Mattson 1992), (Burkett & Godkin 1983). It has been suggested that not only is the qualitative approach suited to primary care research, but that qualitative research and general practice have similarities: *“The underlying concerns and approach of general practice medicine are similar to those of the qualitative research tradition”* (Whittaker 1996) (page 310). Whittaker also highlights the main difference between the two activities: whereas researchers are mainly concerned with increasing understanding and knowledge, GPs are orientated towards finding solutions to specific problems. To these ends, the interview techniques of ethnographers and GPs are different. In the clinical interview, one central objective is to fit the problem presented into a medical category so that a solution can be found. In contrast, the qualitative interview aims to *“discover the interviewee’s own framework of meanings, and the research task is to avoid imposing the researcher’s structures and assumptions as far as possible”* (Britten 1995) (page 251).

I found that the similarities between general practice and qualitative research had advantages and disadvantages for me as a GP researcher. On the positive side, my background as a GP meant that I felt comfortable talking to the respondents about health issues in their homes: in some ways it paralleled the experience of carrying out home visits. I also felt confident in the interview situation and able to cope with the few occasions when respondents became upset and emotional. The main challenge for me was to shift from the information-gathering and problem-orientated style of general practice to

the more open-ended style of interviewing which is necessary for gathering qualitative data. This problem has been described by another GP researcher: Hoddinott said, in relation to a study which explored women's beliefs about breast-feeding: "*I have not found it as easy as I expected to flit between these two roles, particularly letting go of my medical framework*" (1997) (311). The transition from the medical to the ethnographic way of thinking may have been easier for me because, unlike Hoddinott, I was not involved in clinical work during the data collection phase of my study.

At an early stage of the analysis, I became interested in the ways my professional background might affect the dynamics of the interviews and the nature of the data collected. I had the opportunity to explore these issues by comparing my experiences with those of a sociologist researcher who was working on a similar project. In the paper which resulted from these discussions, we highlighted the differences in the interview dynamics and data collected, in relation to our contrasting professional backgrounds (Richards & Emslie 2000) (appendix 6). I found that respondents often asked clinical questions and gave detailed accounts of hospital appointments and medical treatments. Respondents from the socio-economically deprived area were frequently deferential, addressing me as "Doctor", but deference was not expressed by the more affluent respondents who, in contrast, tended to align themselves with me by assuming commonality of opinions and experience. These aspects were not observed by my sociologist colleague. We concluded in that paper that professional background has an important influence on the qualitative research process. We stressed that researchers should consider the ways in which their professional backgrounds and personal characteristics can influence the collection and analysis of data.

6.10 Negotiating paradigms

My background and training are in the positivist paradigm. I attended medical school in the early 1980s and followed a traditional medical curriculum in which there was little scope for consideration of the social aspects of health and illness. Therefore, in some ways, the positivist way of thinking comes more naturally to me. During my general practice training, it became apparent to me that although there were many examples of high quality epidemiological and clinical studies in general practice, there was little

research which took into account patients' perspectives. This realisation fuelled my interest in qualitative methods and the interpretivist paradigm.

The process of learning qualitative research involved challenges at several levels. The biggest challenge was reading and understanding the large amount of sociological literature. I felt somewhat disadvantaged in that I do not come from a sociology background so I was having to fill in fundamental gaps in my understanding of medical sociology as well as becoming familiar with the areas of medical sociology which had a direct bearing on this study. Second, it was necessary to shift from the more familiar positivist paradigm and to come to terms with the different assumptions of the interpretivist paradigm; third, I had to become familiar with all aspects of qualitative methodology; and fourth, I had to learn the practicalities of collecting, organising and analysing qualitative data.

The study on which this thesis was based combined quantitative and qualitative elements, and was jointly supervised by an epidemiologist (GW) and a sociologist (MER). The combination of methods and the joint supervision had advantages and disadvantages for conducting the study and writing the thesis. On the negative side, the study was very large: as well as the survey and the qualitative analysis reported in this thesis, I carried out a substantial general practice case-note analysis (Richards, McConnachie *et al.* 2000) (appendix 1). The thesis required me to read an enormous volume of epidemiological, sociological and methodological literature, which at times felt overwhelming, and I occasionally felt frustrated that I was not able to concentrate properly on any particular aspect of the study. On the positive side, I gained a very broad research training: I was exposed to the contrasting philosophical bases of positivism and interpretivism, and I now have experience in both quantitative and qualitative methods. Also, by carrying out a mixed-method study, I was able to consider the benefits and drawbacks of both approaches and learned to move freely from one to the other. Joint supervision meant that I had to be very clear about both the quantitative and qualitative aspects of the study: it was impossible to enter into intellectual collusion with either supervisor or to hide behind jargon. It also allowed for broad-ranging discussions of ideas, and sometimes provided me with the challenge of negotiating carefully between competing paradigms.

Tables (chapter 6)

Table 6.1 Characteristics of the interview respondents: affluent men

Name	Age (mean = 57.6)	Occupation	Social class	Marital status M=married/co-habiting; D=divorced/separated; W=widowed
Andrew	65	Sales manager	II	M
Eric	65	Joiner (retired)	IIIM	M
Frank	61	Clerical worker	IIIN	W
Graham	54	Engineer	II	M
Hamish	63	Teacher (retired)	II	M
Henry	60	Civil engineer (retired)	I	M
Ian	55	Science teacher	II	M
James	52	Police officer	I	M
John	50	Salesman (retired)	IIIM	M
Keith	47	Music teacher	II	M
Richard	58	Engineer	I	M
Robert	65	Manager (retired)	I	M
Sandy	47	Medical researcher	II	M
Simon	65	Physiotherapist (retired)	II	M
Stewart	57	Medical scientist (ret'd)	I	M

Table 6.2 Characteristics of the interview respondents: affluent women

Name	Age (mean = 57.6)	Occupation	Social class	Marital status M=married/co-habiting; D=divorced/separated; W=widowed
Anne	50	Home-help	V	M
Catherine	61	Housewife	-	W
Christine	52	Telephonist	IIIN	M
Elizabeth	60	Auxiliary nurse	V	M
Elsbeth	47	Architect	I	M
Irene	65	Secretary	IIIN	M
Jane	65	Waitress	V	M
Janet	65	Cleaner (retired)	V	W
Judith	55	Medical secretary	IIIN	M
Mairi	63	Domestic (retired)	V	M
Marguerite	57	Teacher (retired)	II	M
Morag	54	Staff nurse	II	M
Rena	65	Laundry worker (ret'd)	V	M
Rhona	58	Home-help (retired)	V	M
Rosemary	47	Teacher	II	M

Table 6.3 Characteristics of the interview respondents: deprived men

Name	Age (mean = 59.6)	Occupation	Social class	Marital status M=married/co-habiting; D=divorced/separated; W=widowed
Alan	65	Labourer (retired)	V	M
Alec	60	Labourer (retired)	V	M
Alistair	54	Builder (retired)	V	M
David	61	Shot-blaster	IV	M
Eddie	65	Site agent (retired)	IIIN	M
Harry	63	Labourer (retired)	V	M
Jack	55	Electrician (retired)	IIIM	M
Jim	65	Fireman (retired)	IIIN	M
Jimmy	57	Army (retired)	IIIM	M
John B	65	School janitor (retired)	V	M
Malcolm	53	Joiner (retired)	IIIM	M
Robbie	51	Tyre worker	IV	M
Roddie	60	Warehouseman (retired)	IV	M
Tom	57	Factory worker (retired)	IV	M
William	63	Warehouseman (retired)	V	M

Table 6.4 Characteristics of the interview respondents: deprived women

Name	Age (mean = 57.7)	Occupation	Social class	Marital status M=married/co-habiting; D=divorced/separated; W=widowed
Aileen	65	Domestic (retired)	V	M
Cath	65	Factory worker (retired)	V	D
Dorothy	51	Home-help	IV	M
Eileen	51	Home-help	IV	M
Ellen	58	Cleaner (retired)	V	M
Jean	60	Checkout operator (ret'd)	IIIM	M
Jeanette	49	Precognition agent	IIIN	D
Joan	62	Shop manager	IIIN	M
Kathleen	56	Shop assistant (retired)	IIIN	M
Margaret	62	Receptionist	IIIN	M
Mary	64	Housewife	–	D
Maureen	53	Play leader (retired)	V	M
Moira	58	Waitress (retired)	V	M
Pat	63	Factory worker	V	D
Shirley	48	Factory worker (retired)	V	D

Table 6.5 Interview response rates

group	contacted n	dead n (%)	unopened n (%)	reached respondent n (%)	no reply n (%)	refused n (%)	agreed n	response rate %
deprived men	41	2 (4.9)	2 (4.9)	37 (90.2)	15 (36.6)	6 (17.0)	15	36.6
deprived women	25	0 (0.0)	1 (4.0)	25 (100)	3 (12.0)	6 (24.0)	15	60.0
affluent men	27	2 (7.4)	2 (7.4)	23 (85.2)	4 (14.8)	5 (14.8)	15	55.6
affluent women	21	2 (9.5)	1 (4.8)	18 (85.7)	2 (9.5)	1 (4.8)	15	71.4
total	114	6 (5.3)	6 (5.3)	103 (89.5)	24 (21.0)	18 (15.8)	60	52.6

Chapter 7 Self-care and lay care

Respondents were asked to describe their responses to chest pain in terms of their beliefs about the pain, their feelings and their behaviour. The study was designed to investigate socio-economic and gender variations in responses, and throughout the analysis, possible associations with those characteristics were explored.

The study was based on interviews with 30 men and 30 women living in two geographical areas of Glasgow which were characterised as 'socio-economically deprived' or 'affluent' according to their Carstairs deprivation scores (see chapter 5). In chapter 6, I justified using residential area to select the sample because the sampling frame was based on community surveys, and because of the well-rehearsed difficulties of assigning social class (based on occupation) to women and to people who are unemployed. My chosen sampling strategy was successful insofar as it provided a sample consisting of people from a wide range of socio-economic circumstances, but it did result in a number of respondents being inappropriately classified as 'affluent' or 'deprived'. The misclassification had different implications for men and women. In general, responses of working-class male respondents living in the affluent area more closely resembled those of working-class men living in the deprived area, than those of their more affluent neighbours. In contrast, many working-class female residents of the affluent area were married to middle-class men, and as expected, their responses were similar to those of their neighbours. The issue of classifying respondents by social class is complex and no one measure can fully capture the circumstances in which people live. In order to present as full a picture as possible, I have presented data on the respondents' occupations as well as their area of residence (tables 6.1-6.4). In retrospect, it may have been helpful, in order to give a more complete picture of respondents' socio-economic status, to systematically collect additional data on the occupational status of the head of the households.

In chapter 6, I have explained that there was a temporal difference between the two community-based surveys. The deprived population was identified in 1995 and the affluent population at the beginning of 1997. The interviews took place throughout 1998. This meant that in the deprived area, the first experience of chest pain was at least 2 years prior to interview, whereas in the affluent area, the experience was sometimes very recent.

Throughout the analysis I was aware of the possibility that temporal difference might reduce the validity of comparisons between the two populations, but the effect appeared to be minimal, an observation which can be explained by considering three issues. First, respondents' recall of their experience of chest pain was related more closely to the intensity of that experience than to the time lapse since the experience, a finding that fits with experiments in oral history and psychology (see chapter 6). Second, within each population there was a wide variation in the length of time which had elapsed since the experience of chest pain, which reduced the importance of the temporal difference between the two populations. Third, although it might be assumed that a longer time lapse from onset of chest pain means that a presentation is more likely to have taken place, the analysis was primarily concerned with understanding the complexities of responses to chest pain rather than ascertaining whether or not the respondent had actually presented.

When respondents were asked to describe their responses to chest pain, they rarely reported a simple linear process involving experiencing the pain, deciding on the seriousness, and then deciding on whether to take action. Their accounts of whether and when to seek medical care often included descriptions of motivating factors and deterrents, triggers to seeking medical care and actions which did not involve formal medical care. These complexities are in accordance with previous work in medical sociology (Tuckett, 1974) (Zola, 1973). Tuckett (1974) argued:

For symptoms, which are recognised by the medical profession as signs of disease, to be taken to the doctor they must be first be perceived as a problem, then defined as something to be taken to the doctor, and then actually taken there. This process of recognition, definition and action can of course be influenced in a powerful way by members of the individuals family or others in a position close to him (page 164).

Respondents' decisions of whether and when to seek medical care were often made after a prolonged period of deliberation, in which they attempted to normalise the symptom in relation to their previous experience and the experience of others around them.

Respondents frequently referred to 'triggers' to seeking medical care (Zola, 1973), such as the death of a family member or being told by a colleague that they appeared unwell. A few respondents were unclear about whether they had actually presented, making statements such as: "*I may have mentioned it [chest pain] in passing*". Because of these

complexities in seeking medical care for chest pain, the analysis did not simply take into account whether or not a presentation had taken place but the whole process of becoming a patient, and the timing of respondents' decisions.

In chapters 7-10 I describe the results of the study. Chapter 8 details the influence of perceived vulnerability of heart disease on responses to chest pain. Chapter 9 describes the impact of previous illness experience. Chapter 10 discusses the influence of previous encounters with health-care professionals. The results section starts with chapter 7, which describes non-medical responses to chest pain including self-care and lay care, and considers how those factors affect respondents' decisions of whether or not to present with chest pain. Chapter 7 opens with a brief review of the relevant literature. Accounts of self-care and lay care were often interrelated but for clarity, they are considered separately, both in the literature review and the results.

7.1 Literature review

7.1.1 Self-care

The term 'illness iceberg' refers to the observation that most symptoms experienced in the community are not presented to a doctor. Evidence for the existence of the illness iceberg has come from studies such as that by Scambler and colleagues (1981), who used a combination of health diaries and interviews to explore the illness behaviour of 79 women aged 16-44 in London. They found that overall, there was just one medical consultation for every 18 symptoms. In other words, most symptoms had been dealt with by the women without recourse to formal medical care.

A useful discussion of self-care has been provided by Dean (1986), who suggests three types of self-care: to do nothing, to self-medicate, and to treat oneself using non-medication treatments. Dean argues that the first of these categories, 'non-action', is traditionally interpreted as the sufferer ignoring their symptoms or delaying seeking care, and that it is often associated with negative psychological traits of the sufferer. Dean points out that researchers rarely consider the possibility that the patient's decision to do

nothing might be the best course of action. For this reason, she argues, the category of non-action has received little attention in research into illness behaviour. Rogers and colleagues (1999a) argue that doing nothing about symptoms is an important and complex category of behaviour. They suggest that it may signify a variety of intentions, including choosing to ignore symptoms and avoidance of the use of services. They also argue that non-action is morally ambiguous: in some circumstances it may denote an “*unwise neglect of symptoms that should and could be responded to*”, in others “*a wise illness-management strategy*” (page 130). In relation to chest pain, denial of the seriousness of the problem can lead to non-action, as is illustrated by a survey of cardiologists (Julian 1996). That survey demonstrated that consultant cardiologists took an average of 48 hours to call for medical help, compared with a population average of between 1 and 2 hours.

Self-medication can involve taking over-the-counter orthodox medications, using complementary treatments or the manipulation of prescribed drugs. There is recent evidence for the widespread practice of self-medication in the UK. In 1994, the cost of over-the-counter medicines in the UK was equivalent to one-third of the NHS drugs bill (Blenkinsop & Bradley 1996). A study by Cunningham-Burley and Irvine (1987) showed that the commonest response of mothers to children’s symptoms was to buy analgesia or cough mixture. In addition to the use of standard over-the-counter medications in the UK, surveys carried out in the mid-1970s and the mid-1980s have demonstrated a large increase in the use of herbal and homeopathic remedies (Elliott-Binns 1986).

Estimates of the use of non-medication self-care vary widely, depending on the definition used. In a survey of illness behaviour, Dean (1986) used a very broad definition of non-medication self-care, which included rest, exercise and relaxation. She estimated that non-medication self-care was used in 76% of common illnesses. Studies which have restricted the definition to the use of appliances and dietary changes have given lower estimates. In Dean’s study, respondents’ commonest reaction to chest pain, not involving medication, was to reduce their pace of activity or to reduce their cigarette-smoking.

Since the advent of thrombolysis for myocardial infarction, there has been considerable research interest in whether self-care leads to delays in seeking medical care for acute chest pain. A recent UK study which interviewed 43 patients about their responses to acute

chest pain found people who had delayed seeking medical care had often first used self-care measures to control their symptoms (Ruston, Clayton *et al.* 1998). It also found that those who used the greatest number of self-care interventions delayed longest. A review of the research in this area concluded: *“The decision to try self-treatment, whether over the counter or prescription medications or by reducing activity, results in significantly increased delay times”* (Dracup, Moser *et al.* 1995)(page 386).

7.1.2 Lay care

In the 1970s and 1980s, a number of studies examined the use of lay care networks. Freidson (1972) coined the term ‘lay referral system’ to refer to groups in society that *“operate to enforce particular views of illness and treatment”*. Such groups may include family members, friends, neighbours, work colleagues and others. From a study of ethnic groups in USA, Freidson proposed that the type of lay referral system experienced by an individual is likely to determine the tendency of that individual to seek medical care. Based on two criteria, the degree of social cohesion in the group and the similarity of the group’s culture with that of the medical profession, he suggested four types of lay referral network. He then showed that the greatest users of medical care were people living in networks with low levels of social cohesion, whose culture was most similar to that of the medical profession. The lowest users were groups with high levels of social cohesion with cultures which were dissimilar from medical culture.

Since this study, other research has explored the relationship between social networks and the use of health services. McKinlay (1973) carried out an interview study to explore the use of lay networks for ante-natal care amongst 87 working class families in Aberdeen. He assessed social networks according to proximity of friends and relatives, frequency of their interactions and duration of friendships. He compared the use of lay networks by people classified as under-utilisers of health services with that by people classified as over-utilisers, and concluded that the under-utilisers were more likely to live with their families.

Scambler and colleagues (1981), in their interview study of women in London, demonstrated that nearly three quarters of symptoms which had presented to a doctor had first been presented to a lay person. That study also found that the outcomes of lay

consultations varied depending on the patient's relationship with the consultant: consultations with family members were more likely to result in subsequent presentation to a doctor than those with other people. The authors speculate that when respondents compared their symptoms with those of their friends, they re-defined their health problems *"as less serious than they had hitherto supposed"* (page 750).

More recently, Rogers and colleagues (1999b) reviewed the literature on the relationship between lay networks and illness behaviour. They suggest that lay networks can reduce the need for medical care by buffering the experience of stress and by providing emotional support, material aid and information. In addition, they argue, social networks *"transmit norms and values about help seeking"* (page 112). In the conclusion to this review, they make the point that although research has suggested the general importance of social networks to illness behaviour, research findings have been *"inconsistent and differ according to condition, type of health action and population group under consideration"* (page 113).

Research into the relationship between gender and lay networks has been somewhat more consistent. Several UK studies have shown that women have larger and more supportive social networks than men. For example, Cornwell (1984), in a study of the health beliefs and practices of 24 families in London, found that *"it was the women much more than the men who were involved in the relationships that held the network together"* (page 4). In addition, research has suggested that it is women who are mainly responsible for the health and health-care practices of the members of these networks (Graham 1990).

Women's greater involvement in the health of others has been offered as an explanation for their greater use of health services (Hibbard & Pope 1983). Hibbard and Pope suggest that women's greater involvement in health matters, along with their greater role flexibility and aspects of childhood socialisation make it more likely that they will seek medical care for symptoms. However, more recent studies have suggested that women's greater involvement in caring for others can lead to a reluctance to present to doctors. For example, an interview study of people who had suffered a myocardial infarction found that many of the female respondents stated that their priority was to minimise their own disability in order to continue in their caring roles (Johnson 1991).

The theme of 'symptom containment', in order to fulfil domestic and caring roles, arose in a recent multi-method study of the use of formal and informal health-care (Rogers, Hassell *et al.* 1999b). Rogers and colleagues explored the relationship between social roles and help-seeking, and found that both men and women held the conviction that ill-health should not interfere with paid work. They suggest that "*the perceived interference with work performance can operate as a trigger to medical consultation. At other times it may act to prevent the seeking of help*" (page 107). Reluctance to allow ill-health to interfere with work was also found in Cowie's study of responses to acute chest pain in which respondents described their attempts to complete work tasks before seeking medical care for chest pain (Cowie 1976).

7.2 Results

7.2.1 Self-care

7.2.1.1 Non-action

Respondents reported a wide range of self-care strategies which broadly fitted with the three categories suggested by Dean (1986): doing nothing, self-medicating and using non-medication forms of self-care. These are discussed in turn.

Many respondents in my study reported that their first reaction to their chest pain was to do nothing. Like Rogers and colleagues (1999a), I found that respondents' decision not to take action was complex and involved several different factors. First, several respondents expressed a general lack of concern about health issues or a genuine belief that their chest pain did not signify serious disease. For example, Jimmy said of his chest pain:

I never panicked or anything. I am not that type tae worry about everythin'. It didn't bother me or anythin', like that, I just forget it. (130)

Similarly, Robert said: “*I just kept it to myself because I kept thinking ‘Oh it’s just one of those things it’ll go away.’*” (420)

Second, respondents expressed anxieties about bothering their doctors and about not wanting to cause a fuss for other people. Alan first got his chest pain while he was having a drink in a pub, and said that his reaction was to ignore his pain because he “*didn’t want no fuss or excitement*” (118). Maureen said, “*I don’t think your doctor’s really got time for all that*” (857), and the following conversation was with Mary:

HR: Even though you thought it might be a heart attack, you decided not to go to pursue it?

R: No, I think they’ve got enough to contend with, doctors, without me goin’ down there and saying “I had an awful sharp pain”. I mean they would think I was nuts. They’d say “Och, M, piss off” (laughs). (374)

The concern about not wanting to bother GPs was more common amongst women than men, and the only group that did not report this concern was the group of more affluent men.

Third, some respondents, such as Graham, judged that it was not necessary to take action in response to their pain because they felt confident about the cause of their pain. Graham said that he knew “*instinctively*” that his pain was not heart pain and therefore did not see the necessity of taking action. He did however eventually mention his pain to his doctor at a later date “*in passing*”. Fourth, there were many examples where non-action seemed to reflect respondents’ denial of the potential seriousness of their symptoms. In some cases, denial meant a reluctance to label their experience as ‘pain’, preferring instead to describe it as ‘discomfort’, or as ‘a sensation’. For example, Rosemary said:

So, actually when you come out of the train station you’ve got to go up quite a steep hill and I actually found that quite painful, not, I don’t mean painful, unpleasant I suppose. (141)

Other respondents, such as Mairi, considered heart disease as a possible explanation for their pain but then chose to play down its significance:

It [angina] did cross my mind 'cause years ago, my husband had angina and it was much the same sort of thing. I sort of half thought on that but I think I actually, you put that sort of thing to the back of your mind sometimes. (275)

There were also examples of outright denial of heart disease. Most cases of this type of denial were in male respondents, and tended to be in men who were concerned to maintain high levels of physical activity. For example, Robert, when he first experienced his chest pain, was advised by his wife that he had angina. However, despite the increasing severity of his chest pain, he continued to paint his bedroom.

7.2.1.2 Self-medication

About one third of all of the respondents stated that in general they did not like taking medications, and four reasons were given for this. First, one respondent expressed a fear that her body would not be able to deal with the drugs: *"I don't really like taking medicines too much 'cause of the liver breaking it down"* (Joan, 478). Second, there was an expressed fear of addiction:

I don't believe in tablets either. I think once you start takin' any of them you get addicted tae everythin'. They're only good for so long...an' that you know. (269)

Third, stoicism: *"I never take painkillers, I've got pain all over the body but I'm used tae it, you know"* (Jack, 166); and fourth, forgetfulness: *"Even when I get pills I just take 2 or 3 and then I forget about the rest. I don't like takin' pills"* (Jack, 145).

In contrast, many respondents talked favourably about complementary therapies such as vitamin supplements, homeopathy and herbalism. Simon explained that he had an interest in homeopathy which came from his parents. He explained that he tries to avoid contact with doctors and then said: *"I'm a fairly strong believer in homeopathic treatment. I tend to, with the little knowledge I have plus homeopathy, try to offset things"* (80). Jeanette also relied on complementary treatments and said:

I take, I just take Dong Quai, that's all herbal stuff. I've always been vegetarian. I've never eaten meat or milk or butter or nothing, absolutely nothing from a cow. (111)

The only group whose members did not mention complementary treatments were men from the deprived area.

Self-medication with orthodox treatments was not a common response to the symptom of chest pain. This may have reflected the general lack of enthusiasm for taking pills, or may have been related to a more specific belief that taking medication was not an appropriate response to chest pain, which is generally regarded as a serious symptom. There were a few exceptions to this. For example, Anne said, when asked what she did when she got chest pain: *"Well, I must've made tea an' that an' I would have maybe like an aspirin or a paracetamol or something"* (526); Rhona said that she took "Rennies" (419); and Roddie said:

I keep eatin' them 'sweeties', co-codamol, and I am a great one for Askit powders. I like Askits, an' I take them an' they seem tae help. (283)

None of the respondents mentioned using complementary therapies for chest pain *per se*, but several men had used them to treat or prevent a recurrence of their established heart disease. For example, Henry said that he had tried *"some American system of trying to get well"*, which *"involved a system of exercises and diet"* (97), and Graham said:

After my heart attack, I read up several books and thought 'If I take the best advice from all of them rather than take drugs, this might be a good idea', so I take vitamins of various sorts. (250)

He went on to say that he took vitamin C, garlic tablets, selenium, zinc, calcium, multi-vitamins, minerals, vitamin E and homeopathic remedies, and that he consulted the alternative practitioner, as well as taking the orthodox treatment of half an aspirin daily.

7.2.1.3 Non-medication self-care

Like Dean (1986), I found that the commonest non-medical self-care response to chest pain was to rest or to reduce levels of activity. Marguerite said: *"If ever I get that feeling, that sort of tightness about the chest, I do ease off. I either walk slower or I stop what I am doing"* (419). Several female respondents described how they had responded to chest pain by relaxing, a response which was related more to relieving stress than to reducing their physical activity. In relation to her first experience of chest pain (which she interpreted as angina), Marguerite's reaction was to lie down and relax:

It felt like a bar across my chest. Now, I had heard that that was angina, and I could even visualise this black two-by-two sort of thing (laughs) pressing and it was really quite a strange thing. I suppose I had read about it and therefore it came to mind. But it was a pressure and it was a feeling of affecting my breathing and obviously painful, not extremely painful, but painful enough for to make me go and lie down very carefully in bed and try and just relax, try and just sort of let everything go. (251)

And Pat, who turned out to have had a heart attack, reported that before she eventually decided to call a doctor, she had first decided to go to bed to rest:

R: He [son] says, 'Go tae your bed', an' I says, 'I don't want tae go to my bed. I just want tae sit here'. So, I brought a blanket oot an' I sat here, then I began tae vomit.

HR: Did you have chest pains?

R: Oh, I had terrible pains an' that boy went oot an' left me, so, I went tae my bed an' I wrote a note an' I says to him, 'If I'm sleepin' wake me up because I'll need tae get the doctor because I feel ghastly'. Even my eyelids felt sore, my fingernails felt sore an' I was vomiting this yellow an' green bile. Oh, it was terrible. (502)

There were several other measures taken by respondents to relieve their chest pain. For example, Jimmy said that he had tried to relieve his pain by pushing on his chest:

I'd read about it where people are getting pain and they go [gestures pressure on chest]...I used to compress my chest a bit, an' bring up a bit of wind and it would relieve it you know. (134).

Three male respondents, including Henry, reported that they dealt with their pain by increasing their level of physical activity:

When I was playing squash, I started getting a bit of tightness in the chest, but I put that down to not being fit enough. So, I just trained harder, you know, I started doing sprints up hills to try and overcome it. (89)

Reducing levels of cigarette-smoking, which was identified by Dean (1986) as a common response to chest pain, was not reported by my respondents. This may have been because I was specifically concerned with immediate responses rather than with long-term prevention strategies.

7.2.2 Lay care

7.2.2.1 Male and female responses to chest pain

Respondents were asked about whether they had discussed the pain or taken advice from anyone else, their reasons for any such consultations and the outcomes of these discussions. In order to contextualise the replies, respondents were asked whether they tend to consult other people for other health problems.

Women reported a greater tendency than men to discuss their health problems with other people. For example, Pat said, when asked whether she talked to other people about her health problems:

Aye, well, I usually phone my sister and I phone M [friend]. My sister's a great believer in the herbal shop and so is M. M will say, 'Have you tried this?' (233)

In contrast, the male respondents often expressed a reluctance to involve other people:

HR: Do you talk to other people about your poor health?

R: Never.

HR: Why is that?

R: There's no much you can dae about it, so I just accept it. (David, 274)

There was no evidence however that men were any less likely than women to discuss their chest pain. Whether they had presented to a doctor or not, 26 respondents (14 men and 12 women) had told somebody else about their chest pain soon after they had experienced it. Lay consultants included family members, work colleagues, neighbours and friends. The 14 lay consultations made by male respondents tended to follow a similar pattern. In most cases, these consultations had been with their wives, who proceeded to take some form of positive action, such as phoning a GP or calling an ambulance. In other cases, women had advised their husband to do one of these things. For example, William said:

I was just starting work when I got the pain and I says to my gaffer 'I think I'll have tae go hame' ... and when I phoned up my wife, she said, 'No, go to the hospital'. (229)

Similarly, Malcolm explained that he had experienced chest pain as he was walking upstairs, and that he had told his wife, who then called for an ambulance. Other men described how their wives had taken an active part in arriving at the diagnosis of angina. For example, Henry described how his wife, who worked in the health service, had arranged for him to have an ECG, and Robert described how his wife, who was from a medical family, had told him that he had "classic angina". Three of the men had consulted people other than their wives: in two cases, the lay consultant was a work colleague, and in one case a barman.

Women's pattern of lay consultation for chest pain differed from that of men. Of the 12 women who had told someone about the pain, only 4 had consulted their husbands. The rest of the consultations were with other family members (daughters, sons and sisters) or with friends, neighbours and work colleagues. For example, Maureen remembered discussing the chest pain caused by rheumatic fever with older women in her workplace:

Goin' back again, when I took rheumatic fever I was workin' in a mill then an' I was only seventeen, an' I used tae say tae aw the older women, 'What's up when you get pains in your chest?' And they says, 'Och, it's indigestion.' (475)

The few consultations women had with their husbands did not result in the women being advised to seek medical care. For example, Rhona reported that she had told her husband about her chest pain, but when asked what she felt that her husband had thought about it, she said: "*He never thought anything about it(laughs). I mean, he just thought 'Oh well.'*" (424).

Women's consultations with other people also had variable outcomes. Several women, some of whom turned out to have CHD, had been reassured by their lay consultants. For example, Rhona, who turned out to have a myocardial infarction, was advised by a friend that her chest pain was not serious:

I've got an older friend at the bowling green. She said 'Och, R, it's alright, it's only indigestion you've got'. I said 'Do you think so? Och well, that's OK then.' (417)

Similarly, Ellen was reassured by friends that her chest pain, which later turned out to be angina, was caused by spondylitis:

HR: You said you thought it was spondylitis, what made you think that?

R: Because talkin' to other people. I says 'It was all doon the one side', and somebody had said 'Well, spondylitis, aye, comes doon fae the neck' an' you get this intae your head an' say 'You couldnae think it could be this [angina].' (338)

A few women were advised to seek medical care by their lay consultants. For example, Elizabeth said, regarding her chest pain: "*My daughters would say, 'Mum, I think you should go back again and see, because I think that's not right'*" (156).

Women varied in whether they chose to accept and act on lay advice. For example, Dorothy made a conscious decision not to follow a recommendation to seek medical help:

When I first started the home help, an old woman said to me, 'If you ever have pain across your chest, go and see about it'. An' I never listened tae her, but really you should because somebody older has more experience of life than you, so sometimes they do know what they're talkin' about. And, actually when I took ill there, I says, 'I should've listened tae that woman, because she was tellin' me the truth.' (702)

Many women reported a reluctance to discuss their chest pain with family members, especially their husbands. Three factors appeared to underpin this reluctance. First, women did not want to worry members of their family. For example, when asked about whether she told people about her breathlessness and chest pain, Rosemary said:

R: No, no. I would just say that the grass was hard going [difficulty mowing the lawn] or something like that but I wouldn't say anything about it in particular.

HR: So if you said to him [husband], 'Oh, I've had this sort of tightness or this breathlessness', he'd be surprised, would he?

R: Probably, probably, yeah. (223)

Second, women often perceived that their husbands would feel uncomfortable about them being unwell. For example, Morag said: "*I mean, he just took it as, 'Oh well'. He hates me being ill. Yes, oh terrified there's anything wrong with you. He backs off immediately (laughs)*" (438). Third, women often perceived that their health needs were of low priority compared with the health needs and general demands of other family members. Mairi, who had suffered chronic episodic chest pain, explained that she had not told anyone about it, and that she had accommodated to the symptoms by taking frequent rests:

I first started taking the pains about, roughly a few months before I went to the doctor but they weren't bad then. Then they started to get really bad; I was so tired I was actually lying down. I wasn't sort of telling anybody, you know, I'd be doing my work and then I'd have to lie down and sort of rest for a wee while. (297)

She then said that she would have taken the same symptom more seriously if it had occurred in another family member:

I sort of just kept saying 'Oh, I'll put it off', you know. I just kept putting it off. Whereas if it was anybody else in the family, I would've had them down there and then, you know....it's funny you don't do it for yourself. (362)

7.2.2.2 Lay referral and social roles

Gender differences in lay consultation for chest pain can be understood in relation to men's and women's social roles. In this sample, respondents mainly conformed to traditional gender roles, in which the women were responsible for domestic matters and the men defined themselves by their paid employment. In addition, both men and women recognised the importance of women's role as custodian of family health. This role seemed to make women reluctant to worry family members about their own health problems. Margaret expressed this when she said: *"I think, to put it in a nutshell, I'm more of a carer than to be cared for"* (1039). The assertion that women were seen as the custodian of family health was supported by four observations. First, wives were present during 10 of the interviews with men, but in the interviews with women, husbands were rarely present. This was equally true of the evening interviews when both were usually present in the house. A systematic search of the transcripts for the words 'husband' and 'wife' showed that nearly all mentions of 'wife' were in relation to the wife giving health advice to the husband. In contrast, the word 'husband' was mainly used by women referring to their own roles as carers. Second, female respondents had greater knowledge of family structure and family ill-health than men, and men often deferred to their wives when asked simple questions about their own families. For example, when asked whether his mother had heart disease, Sandy replied: *"Ehhm no, I don't think so. You'd have to ask my wife about my mother's health"* (504). Similarly, when asked about the deaths of his parents, William said: *"My wife would know about my mother"* (313). Third, there were many reports of female family members being considered responsible for the monitoring of the everyday health of family members, such as buying medications and ensuring that the family received a healthy diet. When I asked Jack whether he ever used non-prescription medications, he said: *"I normally take Askits or something. She'll buy them, I'll no' get them"* (160). And Stewart said, regarding his wife's attempts to control his diet:

Oh, my wife got bloody paranoiac about it, although she's relaxed recently. No, we've always had, ehhm, a very strict control on diet in terms of

cholesterol and fat. And, of course, you know J [wife] is a nurse and midwife and health visitor. (646)

Fourth, women were reported as being more involved than men in the long-term care of family members. Elizabeth describes a typical scenario:

R: I'd my mum, she had dermatomyositis and ultimately was bed-ridden so I nursed her at the time.

HR: Was she living with you?

R: She was living with me. Yes, uhuh.

HR: For how many years did she live with you?

R: About seven years, hmm, and then, of course my father was also there, and when my mum died he stayed with me too and he ended up having Alzheimer's, you know, so I had him too. (241)

There seemed to be an unwritten order of responsibility for caring for ill or elderly parents, starting with daughters, who often shared responsibility with their sisters. Sons only became involved if there was no daughter available. There were several examples of women helping to care for in-laws, but equivalent cases involving men were rare. In the following example, responsibility was shared between two sisters, despite the elderly mother living with a healthy male partner.

It's very hard work because I work full-time and I take care of them an' I've my mother, she had a stroke three years ago. So between my sister and I we help her as well, but she has a home-help and she's a boyfriend as well, so - but you've still got the commitment. (Dorothy, 30)

Many women took their carer role for granted and accommodated the role alongside their paid work and other domestic responsibilities. For example, Margaret described the way that she and her mother had reversed their roles: "*It ended up anyway, she [mother] was the one sitting on my knee*" (205). In contrast, men who were acting as carers often described their resentment. Jimmy, who provided long-term care for several family members, described being "*stymied*" (44), and Richard, who cared for a brother with schizophrenia, said:

Well, it's getting to the bit now where I've had to turn round. I'd an interview with a Dr H up at G (hospital) and told him that enough's enough. I can't do any more. Ehhm, I want to see out the rest of my life, I've got a few more years. (206)

As well as making them reluctant to consult family members, women's desire to continue in their central roles as carers sometimes made them reluctant to seek medical help for their chest pain. For example, Margaret, who was caring for her elderly mother, had experienced chest pain for many years before she sought medical help, and said: "*I just felt, well, there's no way I can take sick. Who looks after my mother?*" (56). She went on to say:

I honestly thought, there's something wrong, naturally, but in a way I was, I just didnae have time to find out. I knew that if I took ill it was more on my sister's shoulders. (299)

And Anne, who got chest pain when her children were still young, said: "*I think between running the job and the children and everything else I didnae go to the doctors about it, you know*" (430).

It was not only the health custodian role which influenced women's responses to chest pain. Women who did not have financial support from husbands expressed a concern that if they admitted to having chest pain, they would be at risk of losing their jobs. For example, Margaret said:

I never spoke to anyone at work about it [chest pain] because I was afraid they'd say 'Well you're no fit for your job' (581).

And Cath, who had waited three years before going to her GP, said, when asked why she had waited so long:

I think actually to be honest with you, I think it was I knew if I went they'd make me stop work, an' I felt 'I need my job', financially, an' I thought 'I'll keep going', you know, I'll be OK, an' that was really the reason. (313)

Men also reported anxieties about ill-health interfering with employment: several men expressed a concern that if they presented an episode of ill-health to a doctor, they would be instructed to stop work or be 'put onto light duties'. There was an important socio-economic difference in the extent of this concern: the fear of losing a job was more pronounced in men in manual employment, partly because physical health and fitness were often prerequisites of employment, and partly because the effects of forced redundancy were particularly harsh. In addition, some of the male manual workers suggested that they would find it difficult to adapt to illness by finding alternative work, by taking sick leave, or by negotiating early retirement. David, who was forced to take time off work because of his arthritis, illustrates some of the consequences of being out of work, including loss of earnings, loss of respect and dependency on the state:

The work, it gives you a good standard of livin' and it gies you a bit ae, know, say, a bit ae respect an' that. You know, I like the fact that maybe I can be independent, an' that, you know. I don't like the idea I have tae rely on the State an' that, you know. I wouldnae like tae think I'd have tae dae that, you know. (194)

The general concern amongst men about ill-health interfering with employment did not seem to deter men from seeking lay referrals or presenting to their GPs with chest pain.

I attempted to examine socio-economic variations in lay referral behaviour. However, this was made difficult because data on social networks were not systematically collected. I did ask all respondents about the structure of their families, the health of family members and the proximity and ease of visiting family members, and extra information was volunteered about the size and structure of families, about respondents' proximity to family members, and about the interpersonal relationships between family members. The main differences in family structure and cohesiveness between the two areas were that in the deprived area, families were larger and geographically closer than in the affluent area. Knowledge of the health of other family members varied across the whole sample, but there were no indications of a consistent relationship with deprivation, and there was no evidence for the stereotype of the 'close-knit' family which is often associated with social deprivation.

Conclusion

This chapter has described the range of self-care strategies and patterns of lay care for chest pain. Self-care measures included doing nothing, self-medication and the use of non-medication strategies. Inaction was underpinned by four factors: lack of concern about the pain; not wanting to worry doctors and others; confidence in knowledge of the cause of the pain; and denial of the possible seriousness of the symptom. Many respondents reported dislike of medications, and few had used orthodox medications to treat their chest pain. Dislike of medications related to fears about their side-effects and addictive properties as well as to stoicism and a belief amongst some respondents that they cannot remember to take tablets. There was a marked enthusiasm amongst many of the respondents for complementary therapies such as homeopathy and herbalism, and two men had used alternative therapies for treatment or prevention of heart disease. The commonest non-medical self-care strategies were physical rest and relaxation. However, two men reported that they had actually increased their physical exertion in response to chest pain.

This analysis has provided evidence for the use of a range of self-care measures for chest pain. The extent of self-care was somewhat surprising given that chest pain is generally known to be an indicator of a potentially serious condition. It seems from the analysis that even for serious symptoms such as chest pain, there is an illness iceberg in which a great deal of symptoms are managed by the sufferer without recourse to medical care. Previous studies, such as that by Ruston and colleagues (1998), have shown that self-treatments may lead to delays in presenting with acute chest pain. This analysis suggests that the same may be true for angina. It has recently been suggested that *“a large research agenda surrounds self-care, which begins with the need to understand patients’ constructions of symptoms and disorders”* (Jones 2000). This analysis has gone some way to exploring self-care in response to chest pain, and may help to illuminate the processes which determine the movement of patients across the self-care/primary care interface.

Lay care was explored by asking respondents who they had spoken to about their pain, and what the outcome of these discussions had been. Twenty-four respondents said that they had consulted a lay person. For the male respondents, most lay consultations were with their wives, and frequently resulted in the men seeking medical care. Women were more

likely than men to consult non-family members and the outcome of women's consultations was more variable. Several women expressed a reluctance to discuss their chest pain with their husbands, because of fears of causing anxiety and a concern that their health problems would not be taken seriously. I suggest that one of the explanations for the observed gender variations in lay referral patterns for chest pain relates to gender differences in social roles. Women generally acted as custodians of family health and often considered their health problems to be of lower priority than the health of other family members. This made them reluctant to cause anxiety in other family members by discussing their own health problems. In addition, caring for others sometimes mitigated against women presenting to their GP.

Previous research has suggested that women's role as custodian of family health might enhance their awareness of health issues and lead to a greater tendency for women to present to health services (Verbrugge 1985b). My analysis suggested that for chest pain, the health custodian role of women may have led to a reluctance amongst them to use family members as lay consultants as well as a reluctance to present to a doctor with chest pain. This apparent contradiction might indicate that illness behaviour in response to chest pain does not follow the same pattern as responses to other symptoms, such as minor illnesses, as established by most previous research in this area. The observation that women's lay consultations often did not lead to a medical presentation may also relate to the finding reported later in chapter 8, that women are generally considered to be invulnerable to heart disease.

Chapter 8 Perceived vulnerability to coronary heart disease

A strong determinant of respondents' interpretation of their chest pain was their perception of their personal risk of heart disease: their 'perceived vulnerability'. Three main factors were found to affect perceived vulnerability: family history of heart disease and ill-health in general; risk behaviours; and identification with high-risk groups and stereotypes, which included perceived differences between men and women. The salience of these factors varied between respondents. For some, family history was particularly important, whereas others talked at length about their risk behaviours. Some factors fitted into more than one of these categories: for example, excessive alcohol consumption was commonly cited as a risk behaviour, as well as being an important defining characteristic of a cardiac stereotype. This chapter deals with the three components of perceived vulnerability. It begins with a review of the literature.

8.1 Literature on perceived vulnerability

Perceived vulnerability was incorporated into one of the earliest and most influential models of illness behaviour (Rosenstock 1966). Its importance has since been reinforced by several ethnographic studies in the UK. Davison and colleagues (1992) carried out a study which involved in-depth interviews with 810 people living in South Wales. Interviews included questions about the causes of ill-health, issues of control over health, and responsibility for illness. The interviews were supplemented with data collected by observation of and participation in local activities. Using these data, Davison and colleagues argued that four 'aspects of life' have a bearing on perceptions of vulnerability to ill-health: the 'self-evident personal differences between individuals', including heredity; the 'social environment', including wealth, occupation and loneliness; the 'physical environment'; and 'luck'. Davison and colleagues suggested that people consider these aspects and make "*routine observations of cases of illness and death in personal networks and the public arena*" (page 678), and they termed this process 'lay epidemiology'. Significantly, Davison and colleagues found that risk behaviour (or lifestyle) did not constitute a separate category but that "*it was only articulated in terms of*

its intimate but varied relationship with the other elements" (page 678). That finding is in contrast to the results of this study.

Heredity, which was identified by Davison and colleagues as important to ideas about disease causation, has been extensively explored in relation to heart disease. A study which was based on data collected as part of the West of Scotland 'Twenty-07 Study' (Ford, Ecob *et al.* 1994) explored the relationship between perceived personal risk of heart disease and perceived family history of heart disease. In 1995/96, 2153 people were interviewed to explore the relationship between perceptions of family history and attitudes to illness and health. That study found, as expected, that compared with people with no perceived risk "*people who say they have a family history of heart disease are more likely to see themselves 'at risk'*" (Hunt, Davison *et al.* 2000) (page 141).

Further insights into the importance of perceptions of family history have been obtained from a two-generation study based on the MIDSPAN study (Hawthorne, Watt *et al.* 1995). In 1996, 1040 sons and 1298 daughters of the original MIDSPAN participants took part in a cross-sectional survey, which included questions about the ages and deaths of parents and siblings, and whether they perceived that "*there were any conditions, weaknesses or illnesses which run in their families*". This quantitative study found that people of lower socio-economic status were more likely to have a positive family history of heart disease. However, perceptions of vulnerability to heart disease were variable: in families in which at least one parent had died of CHD, only a quarter of sons and a third of daughters perceived that they had a family weakness due to heart disease. Compared with the other groups, men in manual occupations were least likely to consider that a parental death from CHD indicated a 'family weakness' due to CHD (Watt, McConnachie *et al.* 2001).

A qualitative interview study based on the MIDSPAN population found that respondents' perception of a family history of heart disease depended on four factors: 'knowledge of the health of family members'; the 'number and closeness of relatives with heart problems'; 'age of affected relatives'; and 'respondents' gender and social class' (Emslie, Hunt *et al.* 1999). Like the quantitative study (Watt, McConnachie *et al.* 2001), it also found that working-class men had a higher threshold than other groups for considering that heart disease in the family constituted a 'family history'.

With regard to cardiac stereotypes and belonging to a high-risk group, some important conceptual background has again been provided by Davison and colleagues who explored respondents' ideas about the types of people likely to get CHD, and from this, suggested the concept of 'coronary candidacy'. They found a wide range of possible candidates for heart disease, including people who are unfit, overweight and who eat too much, and people who are under stress and worry all the time. They concluded that "*the range of conditions and behaviours that are involved in the candidacy system is wide indeed*" and that "*almost any type of person could be a candidate*" (Davison, Davey-Smith *et al.* 1991)(page 13). In relation to coronary candidacy, Davison and colleagues talked about two important figures: the person who has lived an unhealthy lifestyle yet lived to be 90 – this figure he refers to as 'Uncle Norman'; the other, a person who has died young despite leading an exemplary life style, he refers to as "*the last person you would expect*" (page 18). A more recent qualitative study has suggested the predominance of the overweight and bloated stereotype (Ruston, Clayton *et al.* 1998). In this study, I found that ideas of cardiac stereotypes tended to be restricted to the 'overweight and red-faced' and the 'thin and anxious'.

An important determinant of perceived vulnerability and one which interacted with the three other main determinants (family history, risk behaviours and belonging to a high-risk group or stereotype) was gender. Although Davison's study (Davison, Davey-Smith *et al.* 1991) included men and women, it makes no specific reference to gender variations in perceived vulnerability to heart disease. The issue of gender in relation to perceived vulnerability to heart disease has been explored in some depth by Emslie and others in relation to a sub-sample of men and women who had taken part in the MIDSPAN study (Emslie, Hunt *et al.* 2001). Emslie and others found, like Davison and colleagues (1991) and Ruston and colleagues (1998), that coronary 'candidates' were overweight and did not take physical exercise. They also found that "*accounts of coronary candidacy were structured by gender.... Whenever respondents talked about specific 'coronary candidates', they were invariably talking about men*". Emslie and others suggested that these gendered perceptions of coronary candidacy may relate to the 'intersection of age and gender': female heart disease sufferers tend to be older than males and therefore their heart disease might be attributed to the effects of ageing. As well as the study by Emslie and others, which focused on the gender aspects of coronary candidacy, several studies have specifically explored women's beliefs about their heart disease risk.

In the United States, Lisk and Grau (1999) carried out a study based on 5 focus groups with 41 menopausal women who had experienced CHD. That study found that women often failed to acknowledge the seriousness of their chest pain: “*Participants often failed to recognise the significance of risk factors and symptoms, and even denied the presence of disease following diagnosis and treatment*” (page 37). Possible explanations given by the authors for women’s lack of awareness of heart disease were that women attributed chest pain to other conditions; that their symptoms were not typical; that they were unwilling to disrupt their daily routine; and that they thought that they were not at risk or that men were at higher risk. In addition, many of the respondents perceived heart disease as a low health priority compared with ‘women’s problems’, such as menopause and breast cancer. An earlier American study (LaCharity 2000), which involved interviews with 12 pre-menopausal women about their experiences of CHD, identified similar themes. For example, despite having significant risk factors, women generally underestimated their risk of CHD because they felt protected by their young age and gender. This perceived lack of vulnerability often led to delays in seeking medical care. Respondents often reported that they had not been taken seriously by medical professionals and that they had been told by doctors that they were too young to get CHD.

This lack of concern and awareness of heart disease amongst women has also been demonstrated by surveys of women’s health concerns. In the UK, Griffiths (1995) asked 1649 women to name their main health concerns and found an “*overwhelming concern about cancer*” (page 58). Cardiovascular disease was found to be mentioned far less frequently than cancer as the main health concern. In the USA, Legato and colleagues (1997) carried out 1002 telephone interviews with women and like Griffiths, found that women were more likely to believe that they would die of cancer than CHD.

The qualitative studies and surveys mentioned above have been on all-female samples and thus do not allow gender comparisons. There has been very little research into gender variations in perceptions of heart disease. In the Netherlands, van Tiel and colleagues (1998) interviewed 16 women and 12 men identified as having CHD about their knowledge and perceptions of CHD risk. It found equal knowledge amongst men and women about heart disease and demonstrated that both men and women underestimated their probability of getting CHD. Both men and women thought of CHD as a men’s

disease and compared with men, the women in this study with symptoms of heart disease delayed longer in seeking medical care.

8.2 Results

8.2.1 *Family history*

As described above, previous research has demonstrated the importance of family history to individuals' assessment of their risk of heart disease. Family history was important in this study in two ways. First, the extent and nature of ill-health in families provided a context in which individuals made sense of their own health problems, including the symptom of chest pain: it affected respondents' ideas of normality and their expectations of their own health and life expectancy. Second, and more specifically, perceived risk of heart disease was found to be strongly related to perceived family history of heart disease. These two themes will be dealt with in turn.

8.2.1.1 The family context

There was wide variation in the size and structure of respondents' families. The number of siblings ranged from 0 to 10. Ten respondents came from families with 6 or more siblings, and of these, 8 lived in the socio-economically deprived area. Fourteen respondents had large families of their own, consisting of 4 or more children, and of these, 11 lived in the socio-economically deprived area and a further 2 were from manual social classes. Respondents were asked about illness and death in their first-degree relatives and about the age and cause of death of their parents. Some respondents volunteered further information about ill-health in more distant family members and the wider community. There was wide variation amongst respondents in the reported age of death of parents.

Age of death of mothers varied from '30s' to 92 years. Of the 11 respondents who reported maternal deaths under the age of 60 years, 8 lived in the socio-economically deprived area and 3 in the affluent area. Age of death of the fathers ranged from '40s' to

still alive at 89. Of the 12 respondents who reported paternal deaths under the age of 60 years, 6 were from each area and 2 of those in the affluent area were in manual employment. The commonest cause of death in respondents' parents was heart disease, which was mentioned by 39 respondents as either causing or contributing to death. Young parental deaths were attributed, amongst other causes, to heart attack, stroke, cancer, suicide and childbirth. Of the 11 respondents who reported that siblings had died as children or young adults, 8 were from the deprived area. Causes of these deaths included infectious diseases, such as tuberculosis, suicide and road traffic accidents.

In general, respondents from the deprived area had greater exposure to family ill-health: not only were their families larger but there was a greater concentration of reported illness and young death. This concentration of poor health and early death in the deprived area is illustrated by the following excerpts:

R: Me mother died in 1955 at the age of 55, she died with a brain haemorrhage, she was quite healthy, very healthy, she worked on the farm an', scrubbin', oh, a pretty hard worker. An' my father lived to his seventy-odds. My brothers an' sisters, one of them died, my brother died with pulmonary fibrosis.

HR: How many brothers and sisters do you have?

R: Well, I'd seven brothers and three sisters. One died at the age of 14, the wee girl, with scarlet fever, way back in 1933, I was 7, about 6 weeks old or somethin' at that time. I have one brother, he's schizophrenic, he had a few bad accidents with cars an' in the army too. Oh, M (sister) died, she had a heart attack. (Alan, 287)

R: My father was kilt in the war.... torpedoed. I think he was 40 or somethin'.

HR: Hmm. And your mother?

R: She's dead, aye. She took an overdose.

HR: What age did she die?

R: Forty-eight.

HR: So she was young as well. How many of a family were there?

R: Ehh I've three sisters, one's dead now.

HR: Hmm. Any brothers?

R: Nae brothers. There was a brother, B, but I think he was born dead, aye an' another sister. I think she was born still birth an' aw, so I've only, I've two sisters left.

HR: Right. And did you say one of your sisters died?

R: Aye, the middle one died of an overdose.

HR: And how old was she?

R: Just about forty-somethin'. (Roddie, 430)

Not only do these quotations provide examples of extensive exposure to family ill-health of some respondents, but the language used suggests that the experience of poor health is often not considered to be out of the ordinary. For example, Alan conveyed a sense of resignation when talking about the suicides of his mother and his sister by saying: "*Yeah, a bit ae a life, I think she [his sister] just copied...[his mother]*". This sense of illness being part of the fabric of life was evident in some of the other accounts. John told of how his sister had died of tuberculosis at the age of 21 and said: "*It was just one of these things*" (513). Eddie implied that deaths in childhood were nothing out of the ordinary by saying of his brother, who died after a tonsillectomy: "*It was in the days when they took them in tae get their tonsils oot, wrapped in a blanket and gave him tae my mother an' an infection set in*" (628).

Some respondents who reported multiple health problems and who believed that they were destined to die of something else, reported that they felt protected from heart disease. This paradox arose from the perceived logic that an individual can only die of one disease and if they are likely to die of another disease then they must be less likely to die of heart disease. The most commonly mentioned 'alternative' disease was cancer. For example, Elspeth said: "*Families are into one thing or the other [CHD or cancer]*" (357), and Jeanette said: "*There was no history for heart trouble. Cancer, my mum died of cancer and my aunts died of cancer, no, no hearts*" (504). Alec explained that he considered that a number of conditions ran in his family but not heart disease: "*They'd always died wi' cancer of the stomach, lung trouble, somethin' like that, chest trouble, thrombosis an aw' that, you know, but no, never heart*" (543).

The tendency to have lower general expectations of health was stronger in people living in the more socially deprived area. This is probably explained by the larger families in the deprived area and the higher concentration of health problems within these families.

8.2.1.2 Family history of heart disease

Most of the respondents in this study considered their family histories of heart disease to be important in their assessment of their personal risk. For example, Christine attributed her chest pain to angina because of her father's experience of angina: "*I thought I had*

angina because my father had angina” (243). She extended her belief in the importance of family history in relation to the inheritance of her hypertension: “None of us [siblings] have angina but we all do have high blood pressure. We all seem to have been fated with the blood pressure” (263).

For some of the respondents, family history of CHD was particularly relevant. Tom, who said that he was a heavy smoker and had an ‘unhealthy’ diet, reported that his father died of heart disease at the age of 48, and that six paternal uncles had died of CHD before the age of 60. When he answered a question about the cause of his chest pain, he communicated a sense of certainty that he would die of CHD, not because of his risk behaviours but because of his strong family history:

R: Oh, I thought I was havin’ a heart attack.

HR: And why did you think that?

R: Well, as I say, wi’ this runnin’ in the family, it’s always on the mind, you know. Well, it’s always on my mind that if I’m gonnae die - it’s gonnae be a heart attack, know? This is it, I don’t think of myself dyin’ wi’ anythin’ else. (286)

Some respondents demonstrated that they considered family history to be important by stating that they felt protected from CHD because of their negative family history. For example, Alastair said, in response to the question of whether he felt vulnerable to CHD: *“No, I’m quite confident I’m not, there’s been nobody in my family had any heart problems” (347).* Others interpreted their positive family history in a way that allowed them to avoid feeling vulnerable. Cath believed that although her brother had died at a young age of heart disease, this had occurred as a result of stress caused by a road traffic accident, rather than because of a familial tendency. She said: *“I didnae really think it would be through the family or anythin’ like that” (226).*

A few respondents stated that they were not interested in their family history. For example, Eric, whose father had died of a heart attack at the age of 62, said, when asked about his family history of heart disease: *“I never thought ae it. I’m no one of these kinda folks that try tae trace what my dad died ae, my maw died ae” (556).*

Although respondents from both areas were fully aware of the hereditary nature of CHD, a positive family history of heart disease was more often mentioned by people living in the socially deprived area. In addition, the family histories of heart disease, reported by respondents living in the socially deprived area were often more intense, with frequent reports of multiple deaths in young relatives. For example, Jim explained that two of his brothers and two nephews had heart disease and he communicated a sense of resignation to having heart disease by saying, "*The whole lot of us have had angina*" (353).

Respondents from the more affluent area often referred to isolated cases of heart disease in their families and they more often perceived that a positive family history could be 'cancelled out' by leading a healthy lifestyle. Sandy, whose father and grandfather had died of CHD, believed that his positive family history did not count because his father and grandfather were old when they died. Similarly, Rhona believed that the fact that her mother was 'old' when she died meant that there was not really a history of heart disease in her family. She said: "*There was no heart history in our family. Actually, eventually my mum took heart trouble, but I mean she was 76, my mum*" (433).

8.2.2 Risk behaviours

After family history, the most commonly mentioned reason for perceived vulnerability to heart disease was risk behaviours. The importance of risk behaviours (or lifestyle factors) to the perception of personal risk of heart disease has been previously demonstrated by Davison and colleagues (1992). They not only showed that there is a high level of awareness in the general population of cardiac risk factors such as smoking and diet, but also that lay people take into account these behaviours when assessing their own risk of heart disease. Risk behaviours mentioned by the respondents in order of frequency were smoking, poor diet, being overweight, lack of exercise and alcohol. The emphasis placed on each risk behaviour varied between men and women and between people from the two socio-economic areas.

Smoking was the risk behaviour which was mentioned most frequently and with most conviction. There seemed to be no doubt amongst the respondents of the causative link between smoking and heart disease, and interestingly, there was no mention of Davison's 'Uncle Norman' figure. In addition, smoking was generally associated with moral failing

and blame, a theme which will be developed further in chapter 10. Typical responses of smokers to the question “*Do you think you are at risk of heart disease?*” were given by Shirley and Robbie. Shirley said: “*Ahhhm, probably, uh-huh, because I smoke. If I didnae smoke, no, I wouldnae have*” (237), and Robbie said, “*Oh, aye, obviously: I smoke*” (438).

Diet was also frequently mentioned. In some cases, respondents emphasised the aspects of diet which are known to be risk factors for heart disease such as fat content, cholesterol and not eating enough fruit and vegetables. For example, Tom said of his diet:

HR: Do you have an idea of what type of person gets heart disease?

R: Yeah, me.

HR: How do you mean?

R: I do all the wrong things. For a healthy diet, I do the exact opposite, you know. I don't eat the things that they tell you, you know like lots of fruit an', that, know? No, I don't eat fruit and vegetables and stuff like that, you know, I'm inclined to the opposite. (406)

Other respondents emphasised more general aspects of diet, such as the importance of 'eating a balanced diet', eating 'home-made food' or eating 'conscientiously'.

I mean we've got quite a well-balanced diet, we're no' on salads all the time but ehmm no fries and, you know. (Anne, 724).

I feel I'd never neglected myself, you know, I ate good solid food, not fancy food or anything but good home-made food. (Kathleen, 274)

I would say that I feel I should do more exercise, and probably most of my friends tend to eat more conscientiously, healthily than I let myself slip into. (Elspeth, 353)

It tended to be the female respondents who emphasised the more subtle aspects of diet, which probably reflects the finding that on the whole, it was the women who were responsible for buying and cooking food in the family. Many female respondents also made a connection between healthy diet and their physical appearance and with keeping slim:

Well, I wasn't overweight. I mean, I've always been quite slim and active, you know. I always felt that I'd kept, you know, had a reasonable diet. I've always been aware of the importance of having a good diet. (Elizabeth, 437)

Exercise was mentioned by several respondents but emphasised more strongly by the men. This ties in with Blaxter's finding that men tend to place more importance on physical fitness in their assessment of their own health (Blaxter 1990). For example, Henry believed that his chest pain had been caused by his lack of fitness and said: "*When I was playing squash, I started sort of getting a bit of tightness in the chest, but I'd put that down to not being fit enough*" (90).

Although not a traditional cardiac risk factor, several respondents linked heart disease, and general ill-health and premature death to excessive alcohol consumption. For example, Harry described his observation that many of his younger acquaintances had died prematurely because of excessive alcohol consumption:

I've seen hundreds of people that's no here noo, younger than me, I used to say 'Oh he drinks an awful lot', know what I mean? (375)

In the same way that absence of a positive family history of heart disease was often perceived by respondents to be protective, some respondents stressed the protective effects of leading a healthy lifestyle. This is illustrated by the following quotations:

I didnae smoke and I didnae drink although you know, I went oot for a night, I felt I never done anything that woulda caused a heart attack, you know what I mean. You know how they say, 'If you drink a lot an' you smoke a lot'. An' I always went swimmin'. (Pat, 803)

Well, I thought I ate pretty good and I didn't drink. I had a smoke, I stopped it an' started it again. So, see if I can control my cigarettes, well, I thought I was fit fae the walkin' I done. I mean it didnae bother me, I could walk for miles. (Harry, 332)

Some respondents, such as Rosemary, stressed the importance of balance in their lifestyles, believing that risk behaviours could cancel each other out. She said, in relation to her own perceived risk of heart disease:

Well....I don't eat an awful lot of junk foods. I eat fruit and I eat vegetables but then I also smoke as well and I like a drink as well. (419)

With regard to socio-economic status, respondents from the deprived area talked at greater length about their risk behaviours than those from the affluent area. In addition, while respondents from the deprived area talked at length about the harmful effects of smoking, respondents from the more affluent area, particularly the non-smokers, emphasised the importance of 'fine-tuning' their diets, by increasing their fruit and vegetable consumption and monitoring their cholesterol intake, and the importance of physical exercise. These contrasting perspectives may reflect the known positive association between cardiac risk behaviours and socio-economic deprivation (Woodward, Shewry *et al.* 1990),(Shewry, Smith *et al.* 1992).

Although the main risk factors have been presented as distinct in the above discussion, many respondents talked of several risk behaviours occurring in the same person. For example, Malcolm said, when asked why he thought he was at high risk of heart disease: "*Just wi' smokin' and drinkin' an' not daein' much exercise, you know*" (148). In some cases, this concentration of risk behaviours seemed to define a high-risk 'type'. For example, Rhona said, when asked to describe the type of person who might get heart disease:

People that are overweight, and people that smoke very heavy, and people that seem tae over-indulge in eating an' fatty foods an' things. You see, I was like that [indicates very thin] and I don't overeat, in fact, I eat very little an' I'm not into greasy foods or anything. (453)

The idea of there being a stereotypical individual or group who is at risk of heart disease is developed in the next section.

8.2.3 High-risk groups and cardiac stereotypes

Respondents were asked to describe their ideas of the kind of person they perceived to be at risk of heart disease. Most respondents had clear ideas on the subject and believed that cardiac stereotypes could be characterised by their physical appearance, their personalities and their risk behaviours. Stereotypes were often not fixed in the minds of the respondents but were modified according to new knowledge and experiences. For example, Pat said:

Well, you see, I used tae think it was because you were fat and because you drunk a lot an' you smoked, but I know a few people that's died of a heart attack an' they've been thin. (832)

She went on to say:

M's [husband's] friend died, ehh, an' he was just a young man at 44. An' he didnae smoke, he only took a pint, an' he was like that [indicated thin], an he played fitba' an' everything. (838)

Mairi had also changed her mind about the type of person who is likely to get heart disease:

Well, I used to always think it was sort of overweight people that didn't exercise or anything, but lately I've heard of so many young, athletic, you know people that have taken heart problems. (707)

These variations aside, two physical types dominated respondents' perceptions of stereotypes: the red and bloated person, who overeats, drinks alcohol and neglects their health and the thin, wiry person, who is anxious and easily stressed. An example of the former was given by Roddie, who described his uncle as having "*a big hooter, a big square nose which everyone used to call a Belisha beacon*" (394). Roddie went on to say that his idea of a typical victim was "*guys with big bulbous noses (laughs) an' varicose veins*". A second example was given by Mary, who said in answer to the question of what type of person gets heart disease: "*Ahhm, a reddish, purple face, and obese. Ehhm,*

someone with really badly swollen ankles" (395). An example of the thin stereotype was given by Shirley:

I know a few people that's been wiry, very, very thin. I think it's a stress-related thing also, like folk that tend to worry, worry, worry, an' they can worry theirself intae it. (289)

The risk behaviours described in the previous section were often mentioned in relation to high-risk individuals and groups who indulge in many different risk behaviours. Alan answered the question of what type of people he thought were at risk of heart disease by saying: "*Well, the heavy smokers is the worst I think, and drinkers and poor eaters. I thought those were the people that were liable to the heart attacks you know*" (184), and Jeanette described her idea of someone at risk as:

People who drink alcohol, are overweight and don't exercise, basically I mean grossly overweight. I don't mean just a couple of pounds overweight, a stone overweight. (466)

The personality trait most often associated with risk of heart disease was anxiety and the tendency to become easily stressed. Margaret felt that her husband was at risk of CHD because "*he is a worrier*", and whereas she is able to talk about her worries, he "*keeps everything in*" (306). James stressed the importance of appearance and personality type when he described the typical heart disease victim as "*someone with a red face who's always uptight*" (217).

8.2.3.1 Perceived vulnerability and socio-economic status

Socio-economic status was not explicitly mentioned by men or women in relation to cardiac stereotypes, but it was implicit in some of the descriptions. Many of the men from the socially deprived area reported that they felt part of a high-risk group because of their appearance and their lifestyle. For example, Jim, when asked to describe the typical heart attack victim, said: "*Well, I would say a person who's got the same colour face as mine,*

know, mine's normally scarlet" (938). When asked about his perceived risk of heart disease, Robbie said that he thought he was at risk and added:

Maybe I'm just your traditional Glasgow man. Sunday morning we all have a fry-up. We love tae sit there wi' our pints an say tae the boys "You should see the fry-up I had this mornin'" and at the same time, that's a contradiction in itself because you shouldnae be sittin' talkin' like that. You should be sayin', "I had carrots", but we don't, we sit there an' we say, "I had fried bacon and sausages, I had fried bread, tottie scones an' fried egg, the lot, the full Monty!" (444)

Robbie conveys the idea that as a 'Glasgow man' he is expected to behave in a certain health-damaging ways, and that his cultural norms are a more powerful influence on his diet than knowledge about what is 'healthy'. David also demonstrated his awareness of the high risk associated with living in Glasgow when he said:

I just know the research. The east end ae Glasgow where the heart attacks are more prominent than in any other part of the west of Scotland, the west side ae Scotland an' the most prominent in the heart attacks than any place else in the British Isles. An' I think the east end ae Glasgow is the highest. (667)

He went on to say: "*If you are looking for a candidate for a heart attack, you've come tae the right area, if you know what I mean*" (674). Other respondents were aware of the high risk of living in a socially deprived area. For example, Robbie replied to the question of what type of people are at risk by saying: "*I could take you doon to my wee sports an' social club and point out about twenty of them*" (516).

Some respondents from each of the two areas believed that more affluent people are at particularly high risk of heart disease. For example, Kathleen said about people who are at risk of heart disease:

I would actually think to myself that it's mostly the jet-setters who are rushing around an' drinking, smoking, having a great time to theirself an' everything. Plenty money, just live life to the full and, as I say, doin' drugs an' everything else. I think they're likely, more likely to get heart disease than the poor people because they don't have that style of life. I cannae say it's easier for

them because it's not, but they've nothing more, nothing strenuous to do, like the strain of keeping up with the Joneses. (310)

Richard, from the affluent area, associated heart disease with an affluent lifestyle. The phrase 'it's your turn now' suggests that he perceives that he belongs to a group in which playing squash, playing golf and getting CHD are nothing out of the ordinary:

R: I thought I was heading for a coronary thrombosis.

HR: Did you?

R: Yes... I'd read about it, heard a lot about it and thought, 'Well it's your turn now.' You hear so much about people who are physically fit keeling over on the squash court, the golf course, so I just, right away, didn't take any chances. (351)

The degree to which respondents identified themselves as conforming to a stereotype or belonging to a high-risk group varied with socio-economic status. Respondents from the deprived area often implied that they were part of a group which was vulnerable to heart disease. In contrast, respondents from the more affluent area often distanced themselves from the stereotypes by using the third person in their descriptions. Sandy said of people who typically get heart disease: "*Ehhm, go and stand out at the pub at closing time and see them and their beer bellies and the cigarette up*" (640). Similarly, Rosemary referred to people at risk of CHD as "*they*":

They'd probably be a bit overweight. Smokes and drinks too much probably. Ehh, eats the wrong things or too well. Somebody who doesn't maybe do an awful lot of exercise (490).

The degree to which respondents identified with heart disease stereotypes was also reflected in their choice of illustrative examples. Respondents who did not identify closely with cardiac stereotypes often gave examples of public figures such as entertainers and footballers. In contrast, those who believed that they and people like them were at risk tended to illustrate their ideas of cardiac stereotypes by referring to family members with heart disease. For example, Alec answered the question of what type of person he thought would be at risk of CHD by saying:

Yeah, the typical, he smokes, drinks too much an' overweight, bad diet, you know what I mean, things like that. That's my idea of people havin' heart attacks. I mean, that's what happened to my brother because he was massively overweight. (510)

Regardless of their beliefs about the association of heart disease risk and socio-economic circumstances, respondents frequently mentioned the importance of stress. Stress was mentioned in many different contexts, sometimes as a 'self-evident personal trait', which has been discussed in relation to cardiac stereotypes, and sometimes as a feature of the 'social environment'. Examples of stress as part of the social environment were given by James, who said: "*I should say the pressure and the stress side of things, I suppose, would be another factor*" (240), and John B who talked about the pressures of a busy life: "*The lifestyle nowadays is definitely in the fast lane, you know what I mean*" (515). Stress was particularly relevant to respondents' ideas about the relationship between heart disease risk and gender, which is discussed below.

8.2.3.2 Perceived vulnerability and gender

The issue of gender is addressed in some detail for three reasons. First, it is one of the main foci of this thesis; second, because the data on gender were particularly rich and informative, and add significantly to our current understanding of the topic; and third, because, despite the repeated assumption in the literature that heart disease is perceived to be a disease of men, there is very little empirical evidence to support this assumption.

Cardiac stereotypes were defined by their appearance, their risk behaviours and their personalities, but their gender was rarely made explicit. However, the assumption that stereotypes were men was often implicit: masculine pronouns were almost always used, and clues about the gender of stereotypes were given in the language used and the contextual references. For example, Aileen described the type of person at risk of heart disease as "*someone who stays in the pub after work*" (384).

To explore the area further, I asked the respondents whether they thought that the risk of CHD is higher in men or women. Fifty-five respondents gave a clear answer. Of these, 42

believed that men were at higher risk, and 7 said women. Of the respondents who said women, 6 were themselves female and 5 of these were from the deprived area. The views of men and women are presented separately.

Nearly all of the men believed that men were at higher risk of heart disease. The main reason given was that men's lives are more stressful than women's or that men are inherently less adept at dealing with stress. The types of stresses most often mentioned were the stress of being the main breadwinner and the pressures associated with inflexibility of working routines. For example, Eddie said, when talking about gender differences in susceptibility to heart disease:

My wife doesnae know what it is to pay a bill. She never sees a bill. She doesnae know what it is to put a stamp on a letter. So I suppose I would be thinkin' along the lines of how we run this household that I would have all the worry. (575)

Some men expressed the view that women were protected from heart disease because they are better at dealing with stress and more resistant to the effects of poor health. For example, Alastair said:

Women, I find, can handle stress a lot more than what a man can do. I'd handle stress within my work environment; I know how to handle it and how to solve it. But the general stress of different things, the kids running about an' then they go out an' work for 6 hours at night, three or four nights as well. No, I'd say women are more able to cope with stress than men are, yeah. (464)

And Andrew expressed a similar view:

I think the weaker sex are definitely the stronger one in the health side of it, I would say in my experience. It's maybe not the case, but I would say that the female species seem to stand up to it [ill-health] better. (435)

Several men talked about risk behaviours, and there was a common belief that, although men are currently at higher risk of CHD than women, this is changing as more women

adopt behaviours which are traditionally male, such as smoking and drinking. Richard commented:

I think women are smoking a lot more nowadays and they're also drinking a lot more from when I was young. When my father went into a pub thirty years ago he didn't see many women there. Now you see more women than men. (520)

Men only occasionally mentioned biological differences between men and women. For example, Stewart was aware of the increased risk of CHD associated with the menopause:

They are at lesser risk prior to the menopause. Ehhm, post menopause the risk increases, unfortunately, so I'm led to understand from the figures we see coming across on the national news. (935)

Like the men, most of the women expressed a belief that men are at higher risk of heart disease than women and believed that this was related to their high levels of stress. Women attributed men's higher risk to the stress of their jobs, lack of employment choices and unemployment. For example, the following conversation was with Rhona:

HR: Do you think of men or women more at risk of heart disease?

R: Well, I always think of men, because I think of the stress of their work. I think a lot of men, the stress of their jobs. I've had quite a few friends an' they retired and died like that, an' it was just the stress of their jobs. (466)

Other women emphasised the stress of possible unemployment on men:

HR: Do you think of men or women at more risk of heart disease?

R: I think men. I think they've got more of a harder life, well, you know, they're out working all the time and there's more stress and strain on them nowadays, especially nowadays, trying to keep jobs. (Mairi, 726)

And yet others believed that men were particularly vulnerable because of the relatively recent withdrawal by women of domestic support and comforts for men:

I think men 'cause a lot of young women don't care now. Whereas when I was young you were in the home for your husband an' his meals an' all, they don't do that now. It seems a case of you get it or you don't. (Aileen, 402)

Like the men, several women believed that men are more vulnerable to heart disease because they have less inherent resistance to stress:

Men, because I think women have got an inner built, like calmin' thing. They've got tae because it's just an everyday thing that they cope wi' children. (310)

Women varied more than men in their views about which gender was at higher risk of heart disease. Six women from the socially deprived area believed that women are at greater risk than men, and again they cited stress as an important determinant. The types of stresses most commonly mentioned by these women were the responsibility of caring for elderly relatives; coping with family problems; and the stress of balancing their competing social roles. Answers given to the question of why they consider women to be at greater risk of heart disease than men illustrate this:

R: Stress and I think we carry more of the, you know, worries, problems and things like that.

HR: What sort of worries?

R: Well, we've got the children. You're with them and if you're no workin' then the husband's at work, an' I think we worry more about the children. I'm no' sayin' that men don't worry, they do, but no' the way a woman does.

(Ellen, 490)

Because women have got more stress in their lives. They take care of their families, workin', you know, I mean, the majority of times it's the women that pays the bills. (Dorothy, 557)

Women who believed that men were at greater risk attributed this to men's indulgence in risk behaviours such as smoking and excessive alcohol consumption. Women tended to be more aware of the biological difference between men and women and several believed that they were too young to get heart disease. For example Rhona, aged 58, said: "*I always think heart people as in their 60s and 70s, you know (laughs)*" (397). Similarly, Elizabeth, aged 60, said: "*I didn't like to think at my age I could possibly have angina*" (285).

Generally, women felt protected from CHD at least until the age of menopause. Jeanette made this point by saying:

I suppose traditionally they say men, but I'm conscious that these days it seems to be reported as much, if not more, in women and probably after the menopause. (378)

Heart disease was generally seen by men and women as a male problem. The exception to this was women from the deprived area who felt that women are at least as vulnerable as men because of their stressful lives. This predominant perception meant that women often failed to attribute their chest pain to CHD. Dorothy and Rhona both had typical angina, but delayed presenting to their general practitioners because they attributed their symptoms to other medical conditions. Dorothy said: "*I just automatically thought it was just – like an asthmatic attack*" (384), and Rhona said:

I just thought it was, I said to my husband, I said, "Oh, I've got dreadful heartburn", I says "This indigestion...", and I kept taking Bisodol an' these Rennies, pumpin' Rennies into myself. (419).

Perceived vulnerability was sometimes influenced by the research process itself. Two of the women felt reassured about their risk of CHD because they had recently received screening examinations as part of the MONICA project. For example, Jean said: "*They tested everything, so I gathered everything was OK*" (372).

Conclusion

Respondents' perceptions of their vulnerability to heart disease related to three factors: their perceptions of family history of heart disease and ill-health in general, their personal involvement in risk behaviours, and their self-identification with cardiac stereotypes and high-risk groups. Perceptions of family history affected respondents' beliefs about their vulnerability to heart disease by providing a context in which respondents interpreted their own ill-health and by informing their ideas about the risk of specific conditions such as heart disease. Risk behaviours, such as smoking and unhealthy diets were universally

recognised as increasing personal risk of heart disease, but the emphasis put on each behaviour varied with gender and socio-economic status. Two dominant cardiac stereotypes were identified, based on physical appearance and personality traits: the bloated red faced individual and the thin and anxious type. Stereotypes were usually male and associated with low socio-economic status. In addition, a common defining characteristic of cardiac stereotypes and high-risk groups was stress.

This chapter adds to our understanding of perceived vulnerability to heart disease in two ways. First, although respondents mentioned some factors which fit with the four interlocking fields identified in the study by Davison and colleagues: 'self-evident personal differences between individuals', 'social environment', 'physical environment' and 'luck' (1992), the emphasis was very different from that study, which was carried out in the late 1980s. My respondents did not emphasise luck in relation to heart disease, nor did they mention aspects of the external environment such as climate and natural dangers. They did perceive that 'self-evident personal differences between individuals', such as heredity, and factors from the 'social environment', such as stress, were important. The biggest departure from the findings by Davison and others was the emphasis placed by my respondents on the importance of risk behaviours. Whereas for the respondents in that study, respondents' lifestyle "*was only articulated in terms of its intimate but varied relationship with the other elements*", for my respondents, lifestyle was central to their perceived vulnerability. Risk behaviours were also important in the ways in which respondents characterised cardiac stereotypes and high-risk groups. It is likely that the different emphasis placed on lifestyle by the respondents in these two studies is related to the emergence over the past decade or so of the 'lifestyle movement' and the increasing emphasis by health professionals, policy-makers, politicians and the media on risk behaviours. My analysis suggests that the lifestyle message has become so internalised that behaviours such as smoking have ceased to be simply behavioural choices but have taken on the mantle of 'self-evident personal differences between individuals', and have become important defining criteria of cardiac stereotypes and high-risk groups. The intense focus amongst the respondents on risk behaviours, which are commoner in the socially deprived area, contributed to the observed socio-economic status variations in perceived vulnerability to heart disease. Later in the thesis, I argue that risk behaviour has also taken on a moral dimension which affects the relationships between individuals and health professionals and the ways in which individuals respond to ill-health.

The second way in which this chapter adds to our understanding of perceived vulnerability to heart disease is by providing important empirical evidence for the relationship between perceived vulnerability to heart disease and gender. It is often stated that women feel less vulnerable to heart disease than men (Sharp 1994a), but because most studies looking at women's beliefs have not included men, this has been a difficult assertion to uphold. This study has shown that men and women do indeed view men as at higher risk of heart disease, and that women often feel protected by their age and gender. The more important finding was that men's perceived greater risk of heart disease was usually attributed to stress. Risk behaviours were not frequently mentioned, and the biological differences between men and women were cited by just one man and by very few women. Of the 7 women who believed that women are at greater risk of heart disease than men, 6 were from the deprived area. Nearly all of these women believed that stress was an important determinant of heart disease risk. In the next chapter, I discuss the influence of the individuals' previous illness experience on their perception of chest pain.

Chapter 9 Previous illness experience

Respondents' perceptions of chest pain were found to be shaped by their wider experience of ill-health. This experience was important in two ways: first, the presence or absence of illnesses other than heart disease determined the availability of alternative explanations for their chest pain; and second, it influenced respondents' ideas about what constitutes 'normal' health, including their expectations of future health and life expectancy. This chapter considers the general meaning of illness to the respondents in this sample and explores the two themes: 'ideas of normality' and 'alternative explanations for chest pain'.

The importance of biography has been recognised in previous research. Blaxter and Paterson, in their interview study of working-class Scottish women, showed that women who reported high levels of poor health had low expectations of their health and tended to normalise their illness experiences with respect to their social class, their age and their gender (1982a). In that study women, referring to their social circumstances, talked of poor health as being 'normal' for 'people like us'. They considered medical problems arising from pregnancy and menopause as 'women's troubles' rather than 'ill-health', and often perceived that they were old at a relatively young age.

Cowie (1978), in his interview study of 27 myocardial infarction patients, also recognised the importance of respondents' personal biographies. He said:

We need to concern ourselves with illness behaviour beyond the initial onset of symptoms and in doing so locate perception and evaluation in the sufferer's medical biography and perception of self. (page 314)

Johnson (1991), in her study of adjustment to the experience of myocardial infarction, highlighted the importance of normalisation. She found that respondents normalised their symptoms by taking into account their own preconceived ideas about the nature of a heart attack, and their own vulnerability.

9.1 Illness experience

When exploring the respondents' illness experience, it was necessary to take into consideration the well-rehearsed difficulties in describing ill-health. There has been a tradition in medical sociology of differentiating between 'disease' and 'illness'⁹, and previous qualitative studies have demonstrated that respondents conceptualise ill-health in a variety of ways, including in terms of the consequences of ill-health, such as loss of function and fitness (Blaxter 1985), (Mullen 1993). In addition, diseases can be classified by various criteria, such as chronicity and seriousness (pain, curability and the effect on a person's functioning) (Herzlich 1973). Some authors have advocated classifying diseases as 'stigmatising' or 'non-stigmatising', based on their impact on social functioning, and have suggested treating psychiatric disease as a separate category (Field 1976). In addition, Blaxter (1985) distinguished health 'state', which refers to current health, from health 'status', which refers to health and illness in the longer term.

In this study, I encouraged respondents to express their ideas about their health and illness in their own terms. General questions were followed by appropriate prompts, and in this way respondents were encouraged to summarise their illness biographies. This approach is illustrated in the following conversation with Hamish:

HR: Could I start by asking how you regard your health in general?

R: Pretty well.

HR: Hmm, have you had any health problems in the past? Any specific health problems?

Hamish then reported having diverticulitis, kidney stones, appendicitis and hernias.

Like Blaxter (1985) and Mullen (1993), I found that respondents varied in which aspects of their ill-health they chose to emphasise. Some talked about specific diseases, whereas others talked in more general terms. Some respondents made the distinction between

⁹ 'Disease' is objective and medically defined, whereas 'illness' is subjective, defined by the sufferer (Fabrega 1973). "People respond to illness not disease." (Field 1976) (page 335)

'illness' and 'disease'. For example, Janet said: "*I mean, I consider my epilepsy a condition as opposed to an illness. It's just something that's there, you know*" (463). In addition, many of the respondents gave complex and contradictory statements about their health. For example, Rena answered the request "*I'd like you to give me an idea of how your health is just now*" by saying: "*Well, at the moment it is quite good*" (106). She then explained that she was being treated for diabetes, hypertension, heart disease and stroke. In addition, many respondents emphasised the consequences of their health problems, which included restrictions on their ability to fulfil their usual social roles and everyday activities. For clarity, the results are presented under the traditional headings of 'illness' and 'disease'.

9.1.1 Illness

Epidemiological research has shown conclusively that mortality (Black, Morris *et al.* 1980) and morbidity (Carstairs & Morris 1991a) from most causes increase with increasing socio-economic deprivation. This association was reflected in the accounts of illness of the respondents in this study, who reported varying degrees of health and illness. Forty-four respondents made a clear general statement about their health. Of these, 21 stated that their health was good, 7 judged their health as moderate and 16 said that their health was poor. Of the 16 people with poor perceived health, 12 were from the deprived area, and of the 21 with good perceived health, 15 were from the affluent area. The ways people talked about their health varied depending on whether they summarised their health as 'good' or 'poor'. Those who reported poor health frequently gave answers to questions about the state of their health which seemed rehearsed, with a sense of certainty and conviction. This suggested that their poor health was an accepted and unchangeable aspect of their lives. For example, when Alec was asked about how he viewed his general health, he answered: "*It's knackered (laughs), really, in a nut-shell*" (97), and thus conveyed a sense of finality to his poor state of health. In contrast, those who reported good general health often seemed less certain, with the frequent use of qualifying clauses, such as 'apart from', 'in spite of' or 'as long as'. For example:

HR: How would you describe your health generally?

R: I feel, on the whole I'm healthy, yes. I have one or two problems that don't really impinge on me much. (Marguerite, 62)

Regardless of whether their health was good or poor, many respondents, like those of Blaxter and Paterson (1982a), emphasised the dynamic nature of their health. They stated that their health varied in the short term and in the longer term. Examples of the fluctuating nature of health were provided by John B and Cath:

I have good days an' bad. You know, when I say 'good days', days that I can go about, an' other days I'm just floored, just floored, can't dae nothing, you know. (John B, 244)

Well, I've got my good days, you know, an' then some, you know. You just kinda come an' go. Some days I can get up an' aw no stoppin' me, then other days I, I havenae a breath. (Cath, 71)

In addition to these fluctuations, some respondents, such as Roddie and Tom, reported long-term deterioration of their health:

HR: How is your health generally at the moment, would you say?

R: Ehh oh, deterioratin' aw the time, I'm slowly getting' worse, aye. (Roddie, 101)

HR: How do you feel about your health at the moment?

R: At the moment? At the moment (laughs) I...I feel I'm going down hill rapidly, you know. (Tom, 85)

9.1.2 Disease

General questions about health were often answered with reference to specific diseases or by describing aspects of medical care. This probably reflected the extensive experience of disease and medical care in this sample. The tendency for respondents to medicalise their experiences may have been accentuated by my medical background. Examples of this tendency are given by Rhona who answered a question about her general state of health by saying: "*Well, actually, I've got cancer just now*" (33), and by Judith, who said: "*I'm actually waiting to come up to the W (hospital) on Thursday to see about a gyn problem*" (33).

The diseases most often mentioned by the respondents were those which would normally be classified as serious and chronic. Minor and self-limiting diseases were generally not reported as being important elements of illness experience. The two types of disease mentioned most commonly were musculoskeletal diseases such as arthritis, rheumatism, sciatica and osteoporosis, and respiratory diseases such as chronic bronchitis and asthma. Other commonly reported conditions were hiatus hernia and stomach ulcers, and psychiatric disorders, including depression and anxiety. In addition, there were several reports of hypertension, stroke, thyroid disease, diabetes, cancer and epilepsy. One respondent was registered blind and one was severely deaf. Gynaecological conditions were important in the accounts of the female respondents. For the men, the health effects of alcoholism were frequently mentioned and four respondents stated that they were alcoholic.

As with the variation in reported general health, there were wide variations in reported experience of disease. Some respondents reported no diseases, and others reported multiple serious diseases. This variation is illustrated by the following quotations. The first is from Ian, who, despite repeated prompts, denied any specific diseases (apart from heart disease). The second is from Janet who reported multiple severe health problems.

HR: I want to come back to that again, the chest pain, but is there anything else you've had in your whole life really? Any serious ill-health at all?

R: No, I've just had some growth taken out of a bone up here at the top of my leg when I was about twenty or so.

HR: Yeah. Nothing else at all?

R: No.

HR: Not been into hospital or had any other operations or anything like that?

R: No, nothing, no. (Ian, 62)

HR: Are there any other health problems? You've mentioned several already. Is there anything else?

R: Well, I've got thyroid trouble, under-active thyroid, eh, a couple of collapsed vertebrae in the spine, eh, I've had incontinence for a long time - I've had a lot of operations for that - and osteoporosis, I've had osteoporosis. (Janet, 168)

Another respondent, Rena, with multiple diseases, reported having diabetes, stroke, high blood pressure and high cholesterol, and said laughingly: "*You name it, I've got it, you*

know what I mean?" (113). Respondents with few diseases, such as Rosemary, who reported no health problems apart from eczema in her ears, and Keith, who reported no health problems apart from varicose veins, tended to talk about non-serious conditions. This tendency may have been an attempt by the respondents to give a 'useful' interview, and again may have been accentuated by my medical background.

As well as describing individual diseases, respondents frequently indicated interactions between two or more diseases which had a cumulative negative effect on their health. Four types of interaction were reported. First, one disease was perceived to precipitate another by acting as a trigger or by lowering the body's resistance. This phenomenon was recognised by Blaxter (1993), who found that her respondents connected the events in their health histories as a chain of cause and effect in which one disease would 'go into' another. For example, Christine perceived that her health problems stemmed from a hysterectomy:

I never ever had blood pressure. This has all come since I had my hysterectomy and I went on the HRT an' now I'm on blood pressure tablets. (135)

Second, one disease was sometimes reported to rule out treatment of another. For example, Alec and Rena explained that surgical treatments for their osteoarthritis and CHD had been ruled out because of other health problems:

I need a hip replacement but they cannae gie me any operation because of the chest, you know, so they just says, painkillers for the rest of your life, just suffer. (Alec, 704)

That was when I, the time I took the mild heart attack an' I went to the heart specialist an' they said, 'Goodbye, have a nice life, Mrs H. I can't touch you owin' tae your diabetes, it's too dicey'. (Rena, 185)

Third, some respondents, such as Jeanette, recognised that the treatment for one disease can cause further health problems:

Ehhm, I had, och various things, I don't know, basically all over like a three-year period I was never out of hospitals sorta thing. The last one they took the neck of the womb, it was infected or something an' they took that away and whatever they stitched, they didn't stitch it properly so I ended up in the hospital for about eight weeks or something, you know, because I was bleedin' constantly. (170)

The following statement is from a woman from the affluent area but who was employed in a manual occupation. She reported that her pulmonary fibrosis had resulted from taking prescribed medication:

About three years ago I had problems with my chest and they discovered I had pulmonary fibrosis due to tablets that I was on. I'd been on tablets for nearly three years and low-dose antibiotics and they discovered that they had damaged my lungs. (AF11, 126)

Finally, some respondents described two or more diseases, the combined effect of which was greater than their sum: for example, the combined effects of bronchitis and heart failure were reported to lead to shortness of breath, and the resulting lack of mobility was often exacerbated by arthritis. In addition to the finding that illness and disease were commoner in people from the socially deprived area, it was found that complex interactions between diseases were also reported more often in this group.

Women generally reported a greater number of individual conditions than men and this difference was largely accounted for by gynaecological conditions, such as hysterectomies and the effects of the menopause. These conditions were found to form an important component of the illness biographies of the female respondents. This tallies again with the findings of Blaxter (1993), who said:

There is the constant emphasis on life events, especially those identified with female roles: childbearing, the care of elderly parents and their deaths, the menopause [.....]. Almost every chronic condition had its 'real' origins in one of these events. (page 137)

Some women perceived that the menopause or a hysterectomy was the underlying cause of their chest pain.

9.2 Normalisation of chest pain

In this section I argue that respondents' perceptions of chest pain are shaped by their ideas about what constitutes normal health. Ideas of normality varied widely across the sample: for some, ill-health was reported as unusual; for others, it was portrayed as the 'wallpaper' of their lives. Normalisation of poor health was more common in people living in the socially deprived area. The sense amongst these respondents that poor health had become a normal and accepted part of life was often accompanied by hopelessness and resignation. Normalisation of poor health was found to relate to three criteria: the ability to carry out normal social roles; perceptions of ageing; and ideas about general well-being. The three criteria will be discussed in turn.

9.2.1 *Extent of restriction of social roles*

Previous research has shown that an important defining characteristic of good health is the ability to carry out normal activities (Blaxter 1990, Mullen 1993). Similarly, respondents in this study talked about ill-health in relation to restriction of their social roles. The extent to which chest pain led to restriction of roles depended on the level and type of activities of the respondents prior to the onset of their chest pain, which are described below.

The men and women in this sample generally conformed to traditional gender roles. The men spoke of paid work as their central social role. The women generally spoke of child-rearing, supporting their husbands, looking after elderly or sick relatives and house-work; paid work was often 'fitted in' around other activities. The relative unimportance of paid work for women was stressed by male and female respondents:

I always feel a man has got to work. A woman can do without if need be, you know. If the worst comes to the worst, she can stay at home, you know and make do, maybe not get the extras. (Mairi, 746)

Sorry for me being a male chauvinist [laughs], okay, but in a lot of cases they [women] are not the real breadwinner as such. They can chop and change jobs.

I mean, my wife's had a number of years with the B and a number of years here and a number of years there and all the rest of it. (Andrew, 446)

For the men, there were important class differences in stated occupation and employment status. Of the 15 men in the deprived area, 13 gave their occupation as manual occupations and 10 of these were unskilled. In contrast, 14 of the 15 affluent men gave their occupation as professional or white-collar occupations and 1 was a plumber. In the socially deprived area, 13 men had stopped working, 7 because of redundancy, 3 because of ill-health and 3 having retired at the age of 65. One man was still working and one was unemployed. In the affluent area, 7 had stopped working, 4 because of ill-health, 3 through voluntary redundancy or early retirement, and 8 were still working.

For the women, the occupational division was less clear reflecting the high proportion of women in the affluent area who were employed in manual jobs. Of the 30 female respondents, all except 2 (who stated that they were housewives) identified themselves as having a paid occupation. Four women in the affluent area gave their occupations as professional, 3 as white-collar or skilled manual and 7 as unskilled manual. In the deprived area, 3 women gave a white-collar occupation and 11 were skilled or unskilled manual workers. A total of 7 women worked in jobs such as nursing or home-help which involved caring for the health and welfare of other people.

In addition to there being more redundancy and early retirement amongst men in the socially deprived area, the meaning of being without work differed between men in the two areas. In the socially deprived area, just 2 of the men had made an active choice about their employment status, compared with 10 in the affluent area. Men in the deprived area who had been made redundant because of ill-health often made it clear that they had been forced to stop work against their will. For example, John B, a school janitor, described how the decision for him to retire was made by his general practitioner: "*My doctor retired me, you know*" (64). Frank, another man from the deprived area, described how he was forced by his employer to leave work because he was looking after his wife:

My wife hadn't been too well and she's in and out of hospital and it was just discovered she'd a cancer in the lung and they told me about it an' I took two days off my work. I 'phoned in and told them and I went back the third day

an' they said I'm finished. They said, you're finished because you're gonnae need much time off. (Frank, 57)

For these men, redundancy was often associated with financial hardship, loss of social identity and loss of social contact. Roddie, who had lost his job because of chronic alcoholism, said: "*Aye literally, there's nae aim, there's nothin' to do. You just sit here, read the paper, dae the crossword, telly*" (137).

In contrast to the lack of choice about employment and employment status described by the men living in the deprived area, men from the affluent area described a great deal of control over the decisions of whether and when to stop working. There were several examples of men who had given up work because of ill-health, and who had then adapted by embarking on a new type of career. For example, Keith explained that a heart attack had forced him to give up his job as professional musician at the age of 52, but that he had then re-trained as a music teacher (27). For others, early retirement was viewed positively because it offered freedom from work and provided new opportunities for leisure:

The company was taken over recently, so I decided to opt out when I got the opportunity. So here I am retired and enjoying it. I don't know how I had time to do anything before I retired anyway. (Andrew, 10)

As well as differences in the area of employment, there were variations in the extent to which poor health had led to restrictions in everyday activities and social participation. Respondents with multiple health problems were often severely restricted in these activities and for some, these restrictions had a devastating effect on the quality of their lives. The following quotation is from Frank, a man with chronic bronchitis and emphysema, who was interviewed in July:

I don't want to go out with anybody now, you know. A mate of mine sometimes tries to help me up the road an odd time for a pint but I haven't been out of here since, well, the beginning of the month 'cause I was forced out to a funeral, you know. Prior to that it was March to the dentist. (224)

The following two quotations are from men who felt unable to take part in family activities because of their poor health. They both emphasise the psychological barriers to socialising. Roddie is talking about his daughter's wedding, which took place on the day that I interviewed him. Harry explained that he had become increasingly socially withdrawn since a work-related accident forced him to stop working several years previously.

HR: When you say your health is deteriorating, what do you mean?

R: You don't feel like goin' out, you know what I mean, literally. I mean, the weddin's the day an' I don't even fancy goin', but I've gottae go 'cause I'm goin' in a car wi' her [his daughter]. (Roddie, 109)

I wasnae goin' oot much after the accident. The last few year, the last five year, I don't go oot at aw. I'm actually feart tae go oot mysel'. (Harry, 535)

Social withdrawal was associated with a restriction of leisure activities. For example, Janet said in relation to her worsening health: "*I haven't danced for a long time, I loved dancing and I loved walking. I loved walking in the hills. I thought that was the greatest medicine of all*" (511). John B reported that his general practitioner had advised him to stop attending football matches:

I couldnae dae the things that I wanted tae dae, you know. Used tae go tae football an' I'd tae stop that. The doctor said, 'You cannae go the excitement', an' the team I supported, at that time, there was nothin' tae get excited about, you know, but - that was aw oot the windae, you know what I mean. (231)

Other respondents reported that poor health prevented them from carrying out everyday activities such as walking and shopping. For example, Marguerite said: "*I just feel extremely weary, just unable to, really floppy, just not able to do anything*" (87). John B stressed the importance of his daytime sleep:

No matter what happens I've gottae get that couple of hours in the afternoon because if I don't, I'm no use tae anybody, you know what I mean, so I've gottae get that rest in the afternoon, you know. I'll just go intae my back room there, you know, and ehh, no matter, come hell or high water I've gottae get tae bed." (244)

Restrictions on the ability to socialise and carry out everyday activities were reported more commonly in respondents from the socially deprived area. The degree of the restriction was partly determined by the severity of the health problem itself but was exacerbated by the structural problems faced in the socially deprived area, such as lack of money, poor housing, and lack of social support. Because employment, everyday activities and the ability to socialise were already restricted in many of respondents from the deprived area, chest pain was often not seen as 'out of the ordinary' but as part of the normal daily experience. In contrast, people from the more affluent area often experienced chest pain as a 'bolt out of the blue'. These different perceptions inevitably affected responses to chest pain.

9.2.2 Normalisation with respect to age

I have argued above that respondents whose level of employment and social activity had already been curtailed by ill-health found it easier to accommodate their chest pain as a normal event. This process of accommodation was also related to the respondents' ideas about what is normal health for a person of their age. For example, Shirley, aged 48, gave the impression that her health was beginning to fail because of her age: "*Is this me, 'cause I'm gettin' older? It's like things is startin' tae go sorta wrong, you know what I mean?*" (199). David also related his chest pain to his age: "*Aye ehh, but that's just wi' liftin', and layin', and that you know. And I say, I'm getting older now, I'm 61 an' that, you know*" (398). Previous research has suggested socio-economic variations in ideas about ageing. In their study of working-class Scottish women, Blaxter and Paterson (1982b) asked:

Is the accelerated nature of these women's lives, with early childbearing, grandmotherhood, and resignation to being 'past it' in their twenties and 'getting on now' in their forties, a special feature of the lives of disadvantaged women? (page 193)

Similarly, Gardner and Chapple (1999), in their interview study of the interpretation of chest pain by angina sufferers, commented: "*Patients in deprived areas with high mortality rates perceive themselves as 'old' at a young age, and expectations of treatment are limited*" (page 420). I also found social variations in ideas about ageing. This is illustrated by Roddie, who talked about being congratulated for reaching the age of 59:

R: I'm getting' a lot of pain in my chest for some unknown reason.

HR: Are you?

R: Aye, but I think it's auld age (laughs).

HR: How old are you?

R: Fifty-nine, aye. No I'm fifty-nine on the seventh. I dunno. I've seen a few of my mates goin' away an' a lot, aye they never reached this one. So, the boys are all congratlatin' me, thinkin', 'At least [he made it] to auld age pension' you know, 'cause a lot of them didnae get there. (Roddie, 255)

9.2.3 Normalisation with respect to general well-being

Chest pain was often normalised by respondents in relation to their general health state and levels of fitness. Female respondents often attributed their chest pain to general tiredness. For example, Kathleen said: "*I just thought 'Och, just, you've, I've had to work long hours', you know, so I thought it was just tiredness, that's all*" (224). Men frequently mentioned lack of physical fitness as an explanation for their chest pain. Alastair said: "*An' I knew that's what it was. It was just lack of being fit at the time, that's all*" (341), and James, who had referred to his lack of fitness several times throughout the interview, said, in relation to his chest pain:

Well, I could think of a few possibilities, probably one you would think 'Is it the heart?', secondly, 'Is it something to do with say the digestion side of things?' or is it because I am so fuckin' unfit at the time and not taking enough exercise? (144)

Although respondents frequently mentioned tiredness and lack of fitness in relation to their failing health and their chest pain, there were several examples of respondents who reported that their hard-working lives had made them resilient to poor health. For example, Rena, who had experienced two strokes and diabetes, said that she did not feel vulnerable to CHD because she was "*indestructible*" (619).

9.3 Alternative explanations for chest pain

Gardner and Chapple (1999) suggested that angina sufferers with multiple health problems often lacked confidence in interpreting their chest pain because of confusion and blurring

with other medical conditions, especially heartburn and anxiety. Johnson (1991) found that her respondents, who had all suffered a myocardial infarction, found the subtlety of angina confusing:

Many of the informants were afraid that they would not immediately recognise symptoms such as jaw pain, neck pain and heart burn. Consequently, it often took several bouts of angina before the informants felt comfortable recognising and treating it (page 75).

Similarly, my respondents often expressed confusion when talking about the nature and the cause of their chest pain. One of the reasons for this lack of clarity was that chest pain was often not experienced as a 'text-book' angina, and frequently did not fit with respondents' expectations of heart disease pain. The clinical definition of angina states that it is experienced as 'a band round the chest', and that it can affect the middle of the chest, with possible radiation to the arms and hands, sometimes to the neck and jaw, and occasionally to the epigastric region and back (de Bono & Boon 1991).

Respondents reported a diversity in both the character and the site of their chest pain. Most of the respondents described their pain as being 'tight', 'heavy' or 'sharp'. Tightness was likened to 'a band around me', a 'knot', or 'a grabbing pain'; heaviness was described as 'a bar across the chest', a 'pressing sensation', or as 'crushing'; and sharp pain was described in terms of 'shooting', 'stabbing' and 'like somebody sticking pins in me'. In addition, there were a number of other descriptions, such as 'claustrophobic' and 'like being thumped'. Some respondents, such as Morag, used a mixture of descriptions: "*It was like a heavy weight. It's just there [indicates], a knot just tightens*" (267). Diversity of character of pain was reported even by respondents who had definite Rose angina and a firm clinical diagnosis of CHD. For example, William described his experience as "*one of these jaggy pains*" (237), and Kathleen said that her pain was like "*somebody sticking pins into your body, like a voodoo doll*" (235). This diversity in reported character of chest pain is not surprising when it is considered that pain type was not included in the Rose angina questionnaire because of its inability to distinguish cardiac pain from non-cardiac pain.

There was also variation in the reported site of the pain. One respondent mentioned that his chest pain travelled to his shoulders, another to his forehead and teeth. Some respondents had difficulty locating their pain. For example, Hamish said: *“Just ehh - sometimes it moves about, sometimes it’s in my shoulder, my back, it’s in my chest. It’s all over the place, sort of thing”* (217). Many respondents used body language to communicate the site of their chest pain, a phenomenon which has been observed in a previous study (Edmonstone 1995).

Diversity in reports of the character and site of chest pain could have arisen for three reasons. First, some respondents, despite their positive Rose angina status, may not have had clinical angina. Second, some of the respondents with clinical angina may have experienced ‘atypical symptoms’. Third, linguistic and cultural variations in the sample may have resulted in differences in the descriptions of chest pain.

People in the deprived area were more likely than the affluent group to have multiple complex health problems and therefore they were more likely to attribute their chest pain to conditions other than heart disease. The commonest alternative disease mentioned was respiratory disease. For example, Tom said: *“I think it’s tae dae wi’ this breathing, emphysema thing, you know”* (304), and Alec said:

It’s hard tae say if you’ve got angina attack or the chest pains, ‘cause I get a lot of chest pains through infections, you know, an’ it’s hard to determine one fae the other, you know. (Alec, 338)

Chest pain was also attributed to other conditions such as heartburn and back pain. Dorothy said, *“Sometimes you didnae know if it was heartburn, you know, ‘cause I suffered quite a lot from heartburn”* (Dorothy, 342).

HR: Can you tell me about the chest pain please?

R: Ehh tightness, a shortage of breath and mainly in my back comin’ round, you know, but it was difficult to say because of the pain in my back all the time. (Cath, 587)

Many of the respondents believed that their chest pain related to their usual symptoms and that therefore it did not warrant special attention. For example, David explained that he ignored his chest pain because he considered it to be related to his 'usual cough':

R: I got pains in the chest but I ignore them.

HR: Do you still get them?

R: When I'm coughing like this (laughs). But I don't think it's relevant tae anythin' tae do wi' my heart because they seem to be in the opposite side an' that you know, I think it's mair tae dae wi' coughin' an that, you know. (David, 356)

The tendency to attribute chest pain to other disease was particularly strong amongst men from the deprived area, who often blamed their chest pain on respiratory disease (caused by smoking) or stomach problems (caused by excessive alcohol). For example, Alan reported that he felt vulnerable to CHD because his father had suffered from angina. However, when he got chest pain, he attributed it to 'wind' relating to his alcohol consumption. He was eventually persuaded to seek medical care for his chest pain by the barman in his local pub.

Stress was also mentioned by many respondents in relation to chest pain. The most common situation cited as leading to stress was that associated with caring for elderly parents. Margaret said, "*I blamed her [her mother] for bringing it on. It's just the strain, you know*" (341), and Dorothy said:

I put it down to maybe because of the rushin' about, you know, workin' and shoppin' and you know all the different things, 'cause it's quite strenuous looking after two teenage boys. (412)

In addition to emphasising external stresses, many women attributed chest pain to their own states of anxiety. For example, Joan wondered if her chest pain was caused by her 'nerves': "*These stupid wee niggly pains could be something serious, an' then I think 'It could be nothin' at all.' So I maybe think all this is brought on by my nerves*" (266). The perception amongst the female respondents that chest pain could be attributed to states of anxiety was often reported to be reinforced by the views of medical professionals. This point is discussed further in chapter 10.

Respondents who reported risk behaviours such as smoking and poor diet often incorporated these factors into their explanations of their chest pain alongside alternative diseases. For example, Mairi had considered that her chest pain might be caused by being overweight, or by indigestion, as well as by angina.

First of all I thought sort of indigestion and then I thought, as I say, the weight and, I later thought about it and I thought 'Oh, I wonder if it's something to do with angina' you know, that type of thing. (268)

Some respondents gave lifestyle factors as the main cause of their pain. For example, Kathleen mentioned tiredness and smoking as possible causes of chest pain: "*Oh, I thought, as I say, 'Just a wee strain, 'cause you're tired' and of course I was smoking as well, and so I said 'Och, it's those cigarettes as well'*" (264). Jeanette and John B also mentioned the possibility that their chest pain was directly caused by their smoking:

I'd take it, that's my smokin', you know, that's nothin' other than smokin', I've given it up so many times. (Jeanette, 380)

Well as I say, I thought it was indigestion, an' maybe the smokin' tae. You know how you get people sayin' it's the smokin' goin' for the chest an' that, you know. (John B466).

Mary, another woman from the socially deprived area, said:

I have gave my body one leathering, you know, and it's reacted, I mean it, like everything else, they say the worm turns. My body's turning. It's just saying, you've abused me, now I'll abuse you. (265)

By 'leathering', Mary meant her smoking and heavy drinking.

In addition to respondents confusing chest pain with other conditions, several women expressed a concern that they were already attending the general practitioner frequently with other health problems, and were concerned that their health-care 'entitlement' was

running low. Women often felt justified in consulting for 'women's problems', such as hormone replacement therapy and breast and cervical screening, because of the pressure exerted by health promotion messages and the popular media. However, they were often reluctant to present with chest pain. The following conversation about chest pain was with Maureen, who had consulted frequently with other health problems. As well as expressing concern that she was attending the GP too frequently, she also said that in general, she does not like to 'bother the doctor'.

R: I actually thought then 'Is this the start of a heart attack? No, Jesus God, no', but I don't know, I just left it.

HR: You didn't call your doctor then?

R: No, because at that particular point I thought I was goin' tae the doctor far too much an' I don't know why, I think sometimes the doctor thinks you're playin' on it. And then I say, no I'll leave it just to see, 'cause I'm not one for actually bothering the doctor. (600)

Similarly, Judith said that she had considered the possibility that her chest pain might be angina, but that she did not like the fact that she had several health problems at the same time. In addition, she said that she had decided to put the thought of angina out of her mind:

My husband's brother-in-law has had angina attacks for quite a long time an' he was recently tellin' us about it an' I thought, 'That sounds a wee bit kinda like what this was', but I thought "I'll put it out of my mind." I didnae want to kinda think about it, you know, and I probably don't like the fact that I have several things like that. (197)

Conclusion

In this chapter, I have argued that responses to a specific symptom such as chest pain cannot be understood without reference to an individual's illness biography, which includes their current health state and their expectations of ageing and future health. The first section of the chapter summarises the illness biographies of the respondents and demonstrates that, in general, experience of multiple severe health problems was commoner in the socially deprived area. The chapter then goes on to describe two ways in which illness biography is important to the interpretation of chest pain.

First, illness biography shaped ideas about normality and determined the extent to which chest pain could be accommodated within respondents' frames of reference. People with multiple health problems often had reduced levels of activity and social participation. For them, chest pain was often not regarded as a devastating experience, but as just another health problem. These same respondents often had reduced expectations of future health and life expectancy which contributed to their accommodation to chest pain. In contrast, for respondents who were in good health and who were engaged in employment and other activities, chest pain was more likely to be interpreted as an isolated, unusual, and occasionally devastating event.

Second, respondents with multiple health problems often found it difficult to 'sort out' their chest pain from the symptoms of other diseases. Rather than evoke a new disease, these respondents tended to attribute their chest pain to a disease which had already been diagnosed, such as emphysema or dyspepsia.

Although some research from the 1980s such as that by Blaxter and Paterson (1982a) and Cowie (1978), has stressed the importance of illness biographies and illness contexts for understanding illness behaviour, there has been very little recent research addressing this complex area. The few published studies which address the issue of co-morbidity have been concerned with its definition (Wun, Chan *et al.* 1998) or in the ways that it may underpin social inequalities in survival outcomes (Macleod, Ross *et al.* 2000). In this chapter, I have provided detailed empirical evidence which suggests that illness biography and co-morbidity are strong determinants of the ways in which respondents interpret the symptom of chest pain. In chapter 10, I extend this discussion of co-morbidity and suggest that it can influence respondents' interactions with health care professionals and contribute to socio-economic and gender variations in illness behaviour.

Chapter 10 Previous experience with health professionals

This chapter reports three inter-related findings: first, that illness behaviour in response to chest pain was affected by previous experiences of health-care; second, that previous experiences of health-care varied with social class and gender; and third, that negative experiences of health-care were often related to the underlying belief that individuals are to blame for their ill-health. The chapter begins with a brief review of two areas of literature: the doctor-patient relationship and its influence on subsequent illness behaviour, and the links between blame and heart disease.

10.1 Literature

10.1.1 The doctor-patient relationship and the effect on illness behaviour

A large body of research exists on the nature of the doctor-patient relationship and the general practice consultation. One of two early models of the doctor-patient relationship, advocated by Parsons (1951), was the 'consensus model'. This model assumes that the doctor and patient share the common goal of restoring the patient to health, and that within the relationship, the doctor and patient conform to well-defined social roles. The first major challenge to the consensus model came from Freidson (1970), who proposed that a more appropriate model was one which described the inherent conflict in the doctor-patient relationship. Freidson's 'conflict' model took into account the fact that often patients and doctors inhabit different social and cultural worlds and that they have different priorities. Freidson also recognised that doctor-patient relationships were likely to vary depending on the social background of the patient.

Subsequent empirical work has supported the importance of the social context of the patient in the doctor-patient relationship. For example, Cartwright (1978), in a study which set out to portray the relationships between patients and their doctors, interviewed a sample of people before their consultation, after their consultation and 10 days later. She

found important variations in the doctor-patient relationship which were related to the social class of the respondents. First, the average length of conversation time was longer with middle-class patients than with working-class patients (6.2 minutes compared with 4.7 minutes). Second, despite reporting fewer medical complaints to the interviewer, middle-class patients discussed more problems within the consultation. Cartwright (1978) cites this as evidence that "*middle-class patients were more inclined to discuss their problems with the doctor*" (page 94). She suggests that "*as doctors themselves are middle-class, one might expect them to communicate more easily with their middle-class patients*" (page 96). Third, there were also social-class variations in the extent to which patients were known by their doctors. Doctors said that they would know 90% of the middle-class patients and 82% of the working-class patients if they met them on the street. They also said that they knew where 96% of their middle-class patients lived, compared with 85% of their working-class patients.

A third model of the doctor-patient relationship, the 'negotiation model', is supported by an empirical study by Stimson and Webb (1975), which involved the recording of consultations and interviews with 96 patients in South Wales. Stimson and Webb observed that patients were not passive partners in the consultation and that both doctors and patients employed negotiation tactics. Patients, they argued, muster power in the consultation from outside influences, such as other people in their social networks, and by acquiring their own medical knowledge. Following the work of Stimpson and Webb, Tuckett and colleagues (1985), in a study of 1,300 consultations, examined whether a more equal sharing of ideas was a realistic expectation in the doctor-patient relationship. They showed that in a typical consultation, doctors gave a great deal of information, but failed to listen to patients, that there were low levels of mutual involvement in the consultation and that patients were not treated as experts in their own health-care. Tuckett and colleagues also found important social-class variations in the nature of the consultation: patients from higher social classes and with higher educational attainment were more likely to ask questions and to request clarification of issues mentioned by the doctor.

Since the 1980s, several interrelated societal changes have had an impact on the doctor-patient relationship. First, as argued by Bury (1997c), the ageing population and the increase in chronic illness has changed the nature of 'patienthood'. He suggests that patients have generally become more knowledgeable about their diseases and in some

cases better informed about their particular condition than their GP. Patients are now often the 'expert' in the doctor-patient relationship. Second, the nature of the doctor-patient relationship has arguably been altered by a decline in power of the medical profession (Annandale 1998). Sociologists have argued that this decline has been the result of two broad processes: 'proletarianisation' (doctors' loss of control over terms and condition of work) and 'deprofessionalisation', (doctors' loss of monopoly over medical knowledge) (Elston 1991). Third, Bury argues that there has been an increase in public awareness of the limits of medicine and a related increase in demand for accountability and transparency in medical practice (Bury 1997c). He suggests that the modern doctor-patient relationship is based on a 'contractual model' characterised by the sharing of knowledge and responsibility by doctors and patients and by joint decision-making. Bury defines the contractual model as:

The doctor would provide clear information about treatment options and about the risks and benefits involved. The patient, in turn, would offer to assess the information, be willing to ask pertinent questions and accept a greater level of responsibility in accepting or refusing treatment. (page 98)

Despite the intense interest amongst medical sociologists over the past few decades in social inequalities, there has been little research into social-class variations in the doctor-patient relationship. Stimson and Webb (1975) state that they minimised "*class and cultural factors*" in their analysis for the following reason:

We would hold that the experience of being a patient- transcends the class and cultural differences which affect the type of contact and relations between a particular patient and doctor. (page 110)

More is known about the influence of gender on the doctor-patient relationship. For example, Oakley (1980), in her study of women's views of childbirth, showed that the views and perspectives of women were considered less important than those of the doctor. Roberts (1985), in her study of the relationships between women and their doctors, found that women are often concerned that they are wasting the doctor's time, and their health problems did not warrant a consultation.

There has been relatively little previous research specifically examining the effects of previous experience of medical care on future illness behaviour. Pill (1987b), in a study of illness behaviour in women with cystitis, found that when antibiotics were prescribed by a GP, this reinforced women's beliefs that they should consult a doctor at the onset of symptoms. In that case, previous experience with a doctor increased the tendency to consult in the future. There is also some evidence that previous experience can lead to a reluctance to consult. For example, a recent multi-method study designed to explore the nature and scale of formal and informal health-care utilisation drew the following conclusion:

Negative prior contact with services has the potential to exacerbate unmet need, by reinforcing a reluctance to use services when they are required, and raises questions about the quality of care once contact has been made. (Rogers, Hassell *et al.* 1999c) (page 93)

10.1.2 CHD as the fault of the individual

The moral dimension of ill-health has long been recognised. In relation to his study of the illness behaviour of American undergraduates, Zola (1978) concluded: "*At nearly every level from getting sick to recovery, a moral battle raged*". Since the 1970s, there has been a recognition of an ideology of 'victim-blaming' in which the individual is blamed for their illness (Crawford 1977). This ideology proposes that instead of relying on costly medical treatment, individuals should take more responsibility for their own health.

Although there has previously been very little specific research into beliefs about illness behaviour in response to chest pain, three important empirical studies in the UK have examined the extent to which lay people blame themselves for their health problems.

In South Wales, Pill and Stott interviewed 41 working-class mothers aged between 30 and 35 about their ideas about the causes of illness (the type and severity of illness was not specified). This work was conducted in relation to the shift in official policy from curative to preventative medicine which occurred in the early 1980s. The authors suggest that in order to implement effective strategies for health education, empirical data is needed "*on*

the extent to which the concept of individual responsibility for health is accepted by various groups in society" (page 43). One of the main foci of the analysis was to determine whether these women believed that their ill-health was influenced by individual control or external factors, and explored this by asking the question "*What do you think are the main reasons for illness?*". Approximately half of the women in their sample were fatalistic about the causation of illness, and despite the emphasis in the 1980s on lifestyle as causing disease, the most frequently mentioned cause of ill-health was 'germs'. Twenty of the 42 women referred to lifestyle choices in their discussions of illness causation, and 16 of these 20 mentioned self-blame for ill-health. Pill and Stott suggest that the emphasis on external agents, such as germs, at a time when official emphasis was on lifestyle, might be attributed to a 'cultural lag' between official views and lay perceptions. They argue that the women in their sample had grown up as members of the 'antibiotic generation', in which the germ theory of disease had been emphasised. Although all of the women in this sample were from working-class backgrounds, some class differences were observed: the women who believed that they were morally accountable for their ill-health were less well-educated and less likely to be home-owners than the rest of the group.

At roughly the same time, Blaxter and Paterson (1982a) carried out an interview study of working-class Scottish women about their ideas of illness causation. They found more evidence for perceptions of individual responsibility for ill-health. For example, 20 of the 23 women who suffered from chronic chest complaints smoked, and all except one of them perceived that their smoking was a contributory factor to their respiratory disease. Blaxter comments: "*The self-responsibility theme was paramount*", and adds: "*It was behavioural causes that were offered for almost every disease – certainly in the abstract, or in other people, but also for oneself*" (Blaxter 1993) (page 132).

In 1984/85, the Health and Lifestyle Survey was carried out in England, Scotland and Wales (Blaxter 1990). With regard to perceived responsibility and causation of ill-health, it found that the general public believes strongly that "*voluntary behaviours are the most important determinants of health*". The survey also revealed some important class differences in perceptions. Respondents most exposed to adverse environmental factors, such as poverty, were less likely to cite these external factors as causing ill-health. Also, people with unhealthy lifestyles were most conscious of the links between these behaviours and ill-health.

In 1998/99, Davison and colleagues carried out an ethnographic study in South Wales to explore, amongst other themes, ideas about what constitutes health, the causes of good and poor health and issues of control, fault and blame. The study involved 180 interviews, observation of local activities and informal contact with residents. One paper which resulted from this study presents an analysis of perceptions of the causes and distribution of heart disease (Davison, Frankel *et al.* 1992). A central concern of that study was again the balance between environmental factors and lifestyle in the causation of disease. It demonstrated a high level of knowledge of coronary risk behaviours among lay people, but that knowledge of risk factors did not govern behaviour. With regard to perception of the causes of ill-health, respondents were found to weigh up the influence of personal lifestyle choices alongside other causes, including inherent traits, the social and physical environment and luck. The authors argue: “*British people commonly operate an explanatory framework which regularly includes a moral or quasi-moral judgement of the degree of self-infliction involved in an illness episode*” (page 678). They also argue that “*different disorders [...] have different public images in terms of the likelihood that sufferers have ‘brought it on themselves’*”. It is argued in that paper that diseases fall along a spectrum of ‘blame’, on which diabetes and common infectious disease are associated with least blame and sexually transmitted diseases and lung cancer are associated with most blame. The authors then cite a previous paper, based on the same study, which suggested that CHD causation involves an “*interaction between the explicable and the idiopathic*”, i.e. that it involves lifestyle factors as well as external factors (Davison, Davey-Smith *et al.* 1991).

Besides the work of Davison and colleagues in the 1980s, there has been very little research into lay perceptions of illness causation, relating specifically to heart disease. One exception is a Canadian study which interviewed respondents about the process of adjustment following a myocardial infarction. That study demonstrated that respondents associated heart disease with blame and believed that it is a disease that can be avoided (Johnson 1991). Johnson states:

All of the informants considered heart disease a lifestyle disease; consequently the process of seeking causal explanations was often associated with guilt. It was generally believed that heart attacks occur because individuals do ‘something wrong’. (page 32)

Many of the respondents in that study believed that they were to blame for their heart disease because of the emphasis by health-care professionals on lifestyle factors.

There have been several important empirical studies in the UK which have explored ideas of illness causation in relation to all illness and these are considered in the conclusion to this chapter.

10.2 Results

In my study, when asked about their behaviour in response to chest pain, respondents talked spontaneously and extensively about their previous encounters with health professionals, especially GPs. This finding led me to explore in some detail the nature of these relationships and to examine whether there were any class or gender variations which might then affect behaviour in responses to chest pain.

Respondents' views of doctors related to two criteria: the perceived quality of technical medical care and, more importantly, the perceived quality of the personal relationship with doctors. In a few cases, the distinction between these two criteria was made explicit. For example, Rena said: "*She's a nice wee doctor, she's never done me any harm. I've no' done her any harm, but I do not like her diagnoses*" (304). The quality of the personal relationships related to four factors: the degree to which patients shared the professional and social background of the doctor; the extent of respondents' knowledge; the degree to which information and responsibility were shared; and the extent to which respondents conformed to a healthy lifestyle.

10.2.1 *Social and professional closeness*

In the socially deprived area, none of the respondents were personally connected with the medical profession. This contrasted with 10 people in the affluent area who reported that they or their spouse worked in medical or allied professions. In addition, people living in the affluent area were far more likely to report friendships with doctors. For example,

Richard explained that he was godfather to his GP's first child and during the interview with Robert, his GP phoned to check that he was well, and that he had enough medication for his holiday. Thus several 'affluent' people described having friendly relationships with their GPs as well as privileged access to health-care. For example, Stewart, who worked in a profession allied to medicine, said: "*There's a waiting list for bypasses obviously but in a sense, I'm on an inside track*" (494). Sandy described how he had special access to his GP:

He [GP] is very good as well, because he said, "Oh you're not making appointments hanging around here for ages, ehh surgery finishes at quarter to six. If you come in about five to six on a Monday or Tuesday when I'm working late, just bang on the door and come in and see me." (875)

Stewart, when he experienced his chest pain, approached a consultant cardiologist in the hospital corridor and referred to him, throughout the interview, by his first name.

In contrast, many of the respondents from the deprived area told of their difficulty in accessing medical care. For example, Kathleen explained that prior to being diagnosed with cancer of the larynx, her throat symptoms had been repeatedly dismissed by her GP over a period of two years.

HR: How long had you had the sore throat before you went to your doctor?

R: I'd been goin' to him on and off for about two years with it and complainin' an' just gettin' cough bottles and antibiotics and, of course, everything they blame on smoking. (120)

Some respondents from the deprived area did however suggest the desirability of a common 'understanding' with their doctors. For example, Jim spoke affectionately about his doctor and then said: "*He used tae smoke a pipe, smoke a cigar, he smoked everything but he advised his patients to stop smoking*" (780). Tom also said that this doctor had advised him not to smoke, while tapping his own cigarette against the ashtray. Jim's high regard for his GP did not derive from a belief that the GP's smoking led to better medical care, but because it implied an equality in the relationship.

An interesting paradox in the respondents' views of the medical profession was observed. Although the more affluent people generally reported positive relationships with their own doctors, they often expressed a scepticism towards the wider claims of medical science. For example, Stewart, who was employed in a profession allied to medicine and who enjoyed privileged access, said:

The expectations of the general population have risen unrealistically I think, because at some point, I mean, you [doctors] just don't have the armamentarium to deal with the problems. (980)

In contrast, Kathleen, from the deprived area, reported an unsatisfactory personal experience of health-care but reported that she had great faith in medicine's wider claims:

I keep thinking that this is not the end of me because they're developing things everyday. As I said to Mr R [surgeon], "I'll be a guinea-pig, nothing to lose", you know, I have a lot to gain if something crops up. Ehh I says, "I want to be at the top of the list." My daughter was telling me last week in *Tomorrow's World* - voice transplants. (440)

10.2.2 Knowledge

A study which explored variations in responses to acute cardiac events stressed the importance of 'knowledge of symptoms' in determining these responses:

The most critical factor influencing the time between onset of symptoms and calling for help is that patients and others recognise their symptoms as cardiac in origin. (Ruston, Clayton *et al.* 1998) (page 1060)

Previous researchers have explored the nature of health knowledge. For example, Backett (1992), in a study of the construction of knowledge in middle-class families, distinguished 'lay knowledge' from 'biomedical knowledge'. She argued that a great deal of research into health has begun with "*a biomedically defined issue or problem*", which has "*shaped and constrained our understanding of what lay people consider to be salient health issues*" (page 498). Backett (1992) emphasised the importance of "*examining in depth the inter-*

connections between knowledge, both lay and expert, and its socio-cultural context" (page 505), and others have suggested that in reality, lay people and doctors combine elements of both types of knowledge in their assessments of illness (Helman 1978). In a qualitative interview study of the prevention of coronary heart disease, it was found that respondents report different types of lay knowledge, including 'theoretical knowledge', which arises mainly from technical information, and 'experiential knowledge', which relates to direct experiences such as witnessing disease in family members (Meillier, Lund *et al.* 1997).

My respondents varied with respect to five aspects of knowledge of chest pain and heart disease: its sources, its extent, its accuracy, the level of confidence in their knowledge and the degree to which knowledge was shared within the consultation. These aspects will be considered in turn.

Respondents were asked to describe what they knew about chest pain, angina and coronary heart disease at the time that they first experienced their chest pain, and about the sources of their knowledge. It was evident from the replies that most respondents used both 'theoretical' and 'experiential' knowledge. Theoretical knowledge was obtained from books, health promotion materials, medical professionals, medical relatives and the popular media. Experiential knowledge was obtained by witnessing chest pain and coronary heart disease in family members and social group, and by hearing accounts of these events. Examples of the use of theoretical knowledge came from Helen, who said of heart attacks: "*I've seen them on television and read about them and heard about them*" (315), and from Stewart, who worked in a medically related job:

HR: When you had this discomfort and breathlessness, what did you think it was at the time?

R: I thought I was heading for a coronary thrombosis.

HR: Did you?

R: Yes, because being a person who had a few dealings with the medical fraternity, ehhm I'd read about it, heard a lot about it and thought, "Well, it's your turn now". (343)

Theoretical knowledge was cited more frequently by respondents from the affluent area, which probably reflects their higher level of education, and the greater likelihood of them having personal connections with members of the medical profession. In contrast,

respondents from the socially deprived area were more likely to describe examples of experiential knowledge. For example:

HR: Who was it who had angina, a friend, did you say?

R: A friend, aye.

HR: Yeah, yeah. So you know what angina is like from him?

R: Oh, well, I kinda, the pains he was gettin' were the exact same as I'm gettin' now. I'm talkin' about ten, fifteen year ago. So he's away now, you know, it actually kilt him eventually. (Roddie, 333)

Anne described how she had witnessed her mother having angina attacks and how this experience made her realise that she herself had angina.

It was only through remembering what my mother was like, remembering when we used to take her out. If it was the least wee bit of wind, she would say "Cover your mouth" she'd say to me, although it was herself. And I used to have to cover my mouth because she was covering hers. Now, in a space of a hundred yards, my mother used to have to stop about three times, and I think remembering that made me realise that's what I had. And then I was told it was angina. (1183)

As suggested by previous researchers (Backett 1992), respondents frequently integrated theoretical and experiential knowledge. For example, when asked what she thought was the cause of her pain, Jane said she thought she had angina because "*it must have been something I'd read about it and I just thought, "This is what they've been talking about', and I knew a couple of people who has had angina"* (121).

Respondents varied widely in the extent of their knowledge. Some respondents seemed to know very little about angina. For example, in answer to the question of whether they knew anything about angina, Rhona said: "*No, I was ignorant, I didn't have a clue*" (406), John said: "*Yes and no, I knew just a wee bit about it, you know*" (273), and Rosemary said: "*I just, well, I associate it with severe pain, probably, that's really about all I know about it really*" (296). Other respondents knew much more about angina. For example, Henry, when asked whether he knew what angina was, said: "*Oh yeah, my father died of angina*" (140).

They also varied in the ‘accuracy’ of their knowledge, i.e. the extent to which beliefs concurred with biomedical knowledge. For example, neither Judith nor Alistair appreciated that angina pain can affect both arms. Judith was reassured that her pain went down the right arm, rather than the left, and said: “*Ehmm and strangely enough it’s down my right arm, which I’m glad of*” (145). Alistair was reassured that his pain had not affected his arms:

I know the pains’ll start goin’ down your arms an’ everythin’ like that but it just stayed there in my chest an’ I knew it was exertion at the time, you know. (313)

Mary did not know that pain which gets worse on exertion and improves on rest is very likely to be cardiac in origin:

If I was walking and it came on me, I just sort of slowed down, you know, walk slow and it went away, and I’d say, “That’s what I get for gulping my breakfast.” (240)

Some respondents spoke of the fragility of their knowledge of chest pain, and of uncertainties in interpreting their symptoms, whereas others felt very confident. For example, Jack, a judo expert, who despite his lack of perceived vulnerability attributed his chest pain to heart disease felt very confident in his interpretation:

I just took it for granted that it was somethin’ tae dae wi’ my ticker, aye, obviously, it’s aw that’s there really. I usually know what part of my body’s in trouble. It’s aw doon tae the judo. You tend to know where it’s comin’ fae whether it’s on the surface or whether it’s inside. (261)

A few respondents felt confident enough in their own knowledge to openly disagree with their doctors:

R: After I had the operation Dr L, one of the senior partners, his sort of pet hobby-horse is blood pressure and weight, so that was the way he was going, so I had tablets for my blood pressure and to keep my weight down, but I personally didn’t really agree with him. I thought it was more the cholesterol

side of things.

HR: When you say it's his hobby-horse, what do you mean exactly?

R: Well, if he's sort of dealing with heart or that type of complaint or illness, he thinks that the major problem is blood pressure. He was treating me mainly for high blood pressure which I didn't think I really had, so eventually I, well, he was on holiday so I went to one of the junior partners. (Henry, 260)

Respondents reported wide variation in the extent to which knowledge was shared by their doctors. Some felt that their GP attempted to share information with them. For example, Sandy said:

We [himself and the GP] always sit and have a chat and he says "Oh I read this interesting paper in the Lancet the other day and it says 'da-da-da'".

Other people reported that they were not given enough information. Mary said, after she had had some investigations: "*There couldn't have been anything wrong because my doctors have never said nothing, but they rarely say anything anyway*" (228). Joan said, in relation to her discussions with a doctor about her hormone replacement therapy: "*They [doctors] just say 'you have to do this, you have to do that' and that's it. I'm a question-asker and they don't like me asking questions*" (490).

10.2.3 Extent of conformity to a 'healthy' lifestyle

Like Davison and colleagues (1991), I found that the links between heart disease and risk behaviours were very well understood by respondents: all of my respondents were aware of the links between coronary heart disease and risk behaviours such as smoking, poor diet and lack of exercise. In fact, many of the respondents had become impatient with the over-familiarity of health education messages. Ian demonstrated this impatience by describing the typical cardiac patient as "*someone who's overweight, heavy smoker and drinker, blah, blah, blah*" (205). And Stewart, when talking about the dangers of smoking and poor diet, emphasised the familiarity of the message by saying: "*I do not understand how the general population cannot get this message because it's blazoned out from every pillar and post*" (686).

However, whereas Davison and colleagues suggested that coronary heart disease is attributed equally to lifestyle and to luck, I found that respondents from all backgrounds attributed heart disease to unhealthy lifestyle choices. Following from this, heart disease was frequently 'blamed' on the sufferer. For example, David said: "*You only get what you deserve. The books tell you that and the telly and the papers tell you that*" (David, 589). And Mary, a smoker, described the way in which her father died in his sixties of smoking-related lung disease, before talking about her own chest pain:

I know that emphysema does affect the heart eventually and ... at that time I knew I had emphysema, but it didn't deter me one bit. So I suppose you could say anything I'm getting, I bloody well deserve it because I knew what the outcome was. (Mary, 389)

As well as citing risk behaviours, respondents associated coronary heart disease with a range of negative personal characteristics. The characteristics that were most commonly mentioned were self-abuse and self-neglect. For example, Aileen described her idea of typical cardiac victims as "*people that smoke or abuse theirselves, you know*" (380). Similarly, Harry said: "*I always thought heart trouble was brought on wi' how you looked after yoursel', know? That was my opinion*" (356). Other personal failings, such as selfishness, weakness and laziness were also mentioned. For example, when Dorothy was asked what she believed makes people vulnerable to heart disease, she answered: "*Eatin' wise and not thinkin' ae other people before yourself*" (463). Rena answered the same question by saying: "*People that drink or weaklings*" (449) and Eileen said: "*I think if you were a sort of lazy layabout and suddenly got up and asked the heart to do all these things you might have problems*" (742).

Respondents who believed that they did not 'deserve' to get coronary heart disease also talked about the idea of blame. Several respondents reported the belief that they were protected by hard work from ill-health in general and heart disease in particular. For example, Harry said: "*I wasnae one for sittin' aboot. I'd need tae be daein' somethin', even daein' a day's hard work. I did work hard*" (307). Other respondents, mainly from the affluent area, reported feeling cheated because they had CHD despite their healthy lifestyles. For example, Sandy complained that he had "*fallen through the net, despite doing everything right*" (459), and Stewart, who got CHD at a young age, said:

It niggles me and I have to admit, if you look at me I'm skinny and I don't smoke and I'm fairly active and why the hell should I get a cardiac disorder?
(620)

The association of CHD with poor lifestyle was frequently linked with negative encounters with health professionals and a reluctance to consult for chest pain. For example, Eileen explained that her negative experience of a medical encounter had deterred her from seeking care for her chest pain:

I says to Dr P, 'I really don't feel well'. He says, 'What's wrong?' I said, 'I've got this pain here, I've got that pain there, I've got a chest infe...' 'ONE THING AT A TIME!' And whatever one it was that sorta entered his brain he gave me a prescription for, which meant that from head to toe I was feeling lethargic, under par, maybe even a tonic would've helped me, but I never got that far. (709)

Many other respondents emphasised their fear of being 'told off' by their GPs. This fear was often linked with their alcohol consumption or smoking habits. For example, Rosemary reported that she had not presented her chest pain to her GP because she believed he would chastise her for smoking:

HR: Did you ever think about even going to the doctor with your chest pain?
R: No.
HR: Why was that?
R: 'Cause I probably knew what he would say.
HR: What would he say?
R: (Laughs) 'Stop smoking', yeah. (Rosemary, 202)

And other respondents believed that their GPs would automatically attribute their symptoms to their risk behaviours. For example, Roddie said of his GP: "*He's a wee bit alcohol-biased. Well obviously he's blamin' that for aw these symptoms I've got*". He then explained his reluctance to present with chest pain:

If I go up tae him wi' anythin' wrong he's sayin' it's the booze (laughs), an' so, slap, slap, forget it. So I don't bother too much. If the Soshies [social services] say I need a sick line, I go up an' he'll say 'Here, there's three years, but don't bother me, you know.' (Roddie, 242)

Kathleen expressed a similar concern about smoking:

Of course, everything they blame on smoking, 'You stop your smoking.' God, if everybody stopped smoking everybody should be completely healthy, do you know what I mean? That's the way I look at it. (121)

And Jane and Mairi were concerned that if they presented with their chest pain that the GP would chastise them for being overweight:

First of all he'll say 'You're overweight', and then he'll ask me if I smoke, which I do, and then I'll be in trouble, so that's two of the reasons that I don't go. (Jane, 237)

He's always just saying, 'Oh get the weight down', you know and as I say, it was when I started taking this terrible pain up here, as I say, I went then and he said it might be hiatus hernia. (Mairi, 170)

10.2.4 Social-class and gender variations in previous encounters with medical professionals

10.2.4.1 Social-class variations

I have demonstrated wide variations in the perceived quality of doctor-patient relationships. It seemed from this analysis that this variability was related to three factors: the social backgrounds of the doctor and patient; the extent of their knowledge of health and illness; and the degree to which the benefits of a healthy lifestyle are acknowledged and adhered to. By definition, doctors are of high social status and have extensive knowledge of health and illness. In addition, it is likely that although doctors do not necessarily adhere to healthy lifestyles, they generally acknowledge their value and advocate them. Respondents, on the other hand, varied much more in relation to all three aspects of the relationship, and this variability was associated with the socio-economic status of the respondent. Respondents from the affluent area more likely to share a similar social and professional background with their doctors, they were more likely to use

theoretical knowledge and to enjoy shared knowledge with their doctors and they were more likely to acknowledge and conform to a healthy lifestyle. These similarities with their doctors meant that respondents from the affluent area perceived their relationships with their doctors as being characterised by respect and shared responsibility.

Social-class variations in the quality of the doctor-patient relationship were found to lead to social-class variations in illness behaviour for chest pain. The most significant determinant of social variations in consulting behaviour was the perception amongst people from the deprived area that they were to blame for their health problems because of their indulgence in 'unhealthy' lifestyles. This self-blame led to feelings of poor self-esteem and demoralisation, which led to a reluctance to seek medical care for chest pain.

Demoralisation amongst people living in the deprived area gave rise to a perception that their health problems deserved lower priority than those of other people and compared with the other demands on the GPs' 'valuable' time. A typical comment was: "*I feel I'm wastin' people's time, you know. There's more people out there iller than I am, you know*" (Jeanette, 357). The perception that their needs were of low priority and the feelings of demoralisation were often reinforced by actual encounters with medical professionals. Several respondents reported that their symptoms had been dismissed as unimportant. For example, Roddie said:

Aye, I've telt him, aye, och, he did nothin'. That's it. The wee guy just gies you three-year sick-lines. He doesnae want to do much. I think he's quite happy wi' the patients he's got without me addin' tae it, you know. I very seldom get him oot. (352)

And others reported that they had been chastised for their unhealthy or 'bad' lifestyle choices and that this had affected subsequent consulting behaviour. For example, William said, regarding his chest pain:

R: Aye well, I've got a cough, a smoker's cough.

HR: You've got a smoker's cough anyway. And do you tend to go to your doctor with it or.....?

R: No, no.

HR: Why is that?

R: Just, just because I smoke, that's all.
 HR: Yeah, hmmm.
 R: Shouldnae be smokin' anyway. (158)

The sense of demoralisation was sometimes associated with feelings of hopelessness. Some respondents said that not only had they given up on their own health, but that so had the medical profession. This was illustrated by Mary, who had recently tried to commit suicide:

When Dr W saw my hand he was not amused, it was as if, 'You're a bloody fool, you tried to kill yourself, it's self-inflicted, plus the fact you've got emphysema, you're sixty-four, you're on your road out, so bugger off!' That seemed to be the attitude. (142)

Mary went on to say:

I've got to the stage now, I mean it's not fair really saying about the doctors not giving a damn, well neither do I. That's the way I've got. I've convinced myself I'm on the road out. (286)

In summary, many respondents from the deprived area gave examples of negative encounters with health professionals in which they had been confronted by a professional who not only has a greater knowledge about their health than themselves but who also has the authority to criticise their behaviour.

The experience of seeking health care was often perceived as demeaning and disempowering, and added to respondents' existing feelings of resignation and demoralisation about their health. It is not surprising therefore that negative experiences such as these led to a reluctance to present with chest pain. In contrast, people from the affluent area, who were less likely to smoke or eat unhealthy diets, did not in general report the belief that they would be blamed by doctors for their health problems. There was no indication that seeking medical care was tinged with feelings of low self-worth and guilt, and no suggestion that previous encounters with health professionals led to a reluctance to present with chest pain.

10.2.4.2 Gender variations

The case-note retrieval stage of this study demonstrated that women with chest pain were less likely to present to a GP than men (Richards, McConnachie *et al.* 2000) (appendix 1). The qualitative data presented here help to explain this difference. Although the social-class variations described above applied equally to men and women, one negative aspect of the doctor-patient relationship was reported mainly by female respondents. Many of the women expressed a concern that if they went to the GP with chest pain that they would not be taken seriously. In some cases, this concern led women to 'dress up' their chest pain as another symptom. For example, Elizabeth had lived with chest pain for fifteen years, having originally been told that it was due to anaemia. Eventually, the pain got more severe and she became concerned that she had heart disease. She presented to her doctor, but rather than admit to having chest pain, she presented with tiredness:

HR: Did you go back and say that you've had chest pains?

R: Well, no I didn't. I just went back and said that I was feeling very tired.
(171)

Several women believed that doctors did not fully appreciate their concerns about their chest pain and that they had been dismissive. Others reported that doctors had attributed their symptoms to non-serious causes, such as 'poor posture' or 'nerves'. For example, Morag, a woman with previous experience of post-natal depression and anxiety, who was convinced that she had heart disease, said:

What they [medical professionals] are saying is 'You are a bit depressed just now, anxiety levels are all up, stress will affect you.' (526)

Others expressed surprise that their doctors did not appear to consider heart disease as an explanation for their pain, when to them the diagnosis of angina seemed likely. For example, Christine said:

I went to the doctor and said to him and he sounded me and you know, I mean the pain had an association with angina. I was surprised he didn't say that.
(726)

Women often tolerated the lack of concern shown by their GPs because they themselves did not feel vulnerable to CHD. Their perceived lack of vulnerability, and the apparent lack of concern by GPs led to women feeling that they were wasting the doctor's time by presenting with chest pain. For example, Christine, who had been examined by her doctor but not referred for further investigation, said:

I must have had them [chest pains] for a wee while.... you feel you go to a doctor and you feel as though you are bothering him all the time, so you walk in and you say 'Och, it's alright', you know. (208)

Despite the fear of angina, her faith in doctors prevented her from pursuing the issue. She said: "*I just mentioned it. I didn't make an issue and say 'I want to go and find out about it' because I have great faith in the doctors*" (270). The GP eventually made the diagnosis of muscular pain.

Conclusion

This chapter draws three main conclusions. First, there was a wide variation in the perceived quality of doctor-patient relationships. Second, the quality of the doctor-patient relationship was found to affect respondents' tendency to consult. Many respondents reported that previous negative encounters with their GP deterred them from consulting with chest pain. I have argued in the chapter that the reluctance to consult because of previous negative encounters may be particularly relevant in the case of chest pain, because heart disease was commonly associated by the people in this sample as a disease of fault and blame. Third, the quality of the doctor-patient relationship and the tendency to consult with chest pain were strongly linked to the patient's socio-economic status. People from the deprived area more often reported negative encounters with their GPs, based on lack of social alignment, lack of information-sharing, and demoralisation associated with an unhealthy lifestyle. In addition, female respondents frequently reported a perception that their chest pain was not taken seriously by their GPs.

Although I have stated in section 9.1.2 that there has been very little previous research into lay perceptions of the causation of heart disease, it is useful to consider how the

conclusions of this study tie in with the more general research in this area. Three studies which have looked at ideas of illness causation (Pill & Stott 1982) (Blaxter & Paterson 1982a) (Davison, Frankel *et al.* 1992) all suggest that there is a balance between 'external factors' and those which are under the control of the individual. Pill and Stott emphasise the salience of external factors, and Blaxter and Paterson stress the importance of individual responsibility. With regard to heart disease causation, Davison and colleagues introduce the concept of 'candidacy', which takes into account personal attributes and lifestyle but also recognises the unpredictability of heart disease (Davison, Davey-Smith *et al.* 1991). Compared with the respondents in these studies, my respondents seemed to place a greater emphasis on personal responsibility and blame for ill-health in general and for heart disease in particular. There are several reasons why the results of my study cannot be compared directly with the previous research: all of the studies involve different populations; the studies by Pill and Stott and Blaxter and Paterson involved all-female samples; the questions asked of the respondents were not the same; and the earlier studies were all general, rather than about heart disease. However, there is a good theoretical reason why the apparent shift in ideas about illness causation (from a balanced view of external and internal causes in the 1980s and the strong emphasis on self-blame demonstrated by my study in the 1990s) might be real. It could be explained by the widespread acceptance throughout the 1990s of the predominant health promotion of the 1980s, that health and illness are the responsibility of the individual.

In addition to suggesting that the main perceived cause of heart disease amongst my respondents is individual fault, I have explored the ways in which perceptions of causation can affect illness behaviour. I have suggested that self-blame for heart disease and illness in general can affect the perceived quality of encounters with doctors and in some cases can lead to a sense of demoralisation amongst respondents about their health.

Demoralisation was more evident in respondents who reported taking part in unhealthy (i.e. high-risk) behaviours and amongst these people, it seemed to be linked to a reported reluctance to seek medical care. Blameworthy lifestyles, demoralisation about health, and a reported reluctance to present with chest pain were all associated with socio-economic deprivation. This observation leads me to speculate on whether by emphasising individual responsibility for health, 'the lifestyle message' may discourage people from presenting with chest pain.

Chapter 11 Summary and conclusion

This study was stimulated by previous research demonstrating socio-economic and gender variations in uptake of cardiology services. Despite CHD being the leading cause of death in the UK, and the existence of a vast quantity of literature on the clinical aspects of CHD, very little is known about the factors which determine whether a person with chest pain becomes a patient. With few exceptions, previous research on lay responses to chest pain has focused on the acute symptom, rather than on angina. Those studies, which were reviewed in chapter 4, were inadequate to provide a comprehensive analytic framework for this study, but did provide some useful background. For example, Cowie's study of the perceptions of patients with myocardial infarction found that chest pain was interpreted in relation to respondents' total illness experience, and that symptoms were normalised in relation to the experiences of other people (Cowie 1978). In order to strengthen the analytic framework of the study, I reviewed the general sociological literature on illness behaviour, which enabled me to develop broader themes, such as perceived vulnerability to heart disease.

By building on the previous literature, this study has provided an in-depth analysis of the perceptions of, and illness behaviour in response to chest pain of sixty men and women from a range of socio-economic backgrounds. In relation to the known inequities in access to cardiology services, it has examined the relationship between these perceptions and behaviour and socio-economic status and gender.

An important component of the decision of whether to seek medical care was respondents' reported self-care and lay care strategies. Chapter 7 showed that self-care strategies were used by most of the respondents and included non-action, taking medication and other measures such as slowing down and relaxing. Reasons given for using self-care measures included fear of unnecessarily bothering their doctor, and confidence in their own ability to diagnose and manage their own symptoms. There were very few reports of respondents using orthodox medication for chest pain, which probably reflected a general dislike of medication. Somewhat surprisingly, a number of respondents reported the use of complementary therapies for the treatment or prevention of heart disease.

Most respondents reported that they had discussed their chest pain with a friend, colleague or family member, but the nature of these consultations and their outcomes varied between men and women. Men reported using lay networks to a similar extent as women, which is the reverse of the pattern for general ill-health. Men's consultations for chest pain were mainly with their wives, and most of these consultations led to the man seeking medical help. In contrast, women often expressed concern about worrying their husbands, and consulted friends or neighbours. The outcomes of the women's lay referrals were more variable than those of the men: although in some cases, women were advised to seek medical care, others, who later turned out to have CHD, were reassured by lay consultants that their chest pain was not serious. I suggested that the observed gender variations in responses to chest pain relate to gender differences in social roles: because of their greater involvement in family health matters, women were often reluctant to seek medical care for their own health problems. This reluctance was compounded by their perceived invulnerability to heart disease.

Chapter 8 demonstrated that respondents' perceptions of chest pain are strongly related to their perceived vulnerability to heart disease, which is itself determined by their perceptions of family history of heart disease and ill-health in general; their personal involvement in risk behaviours; and the extent to which they identify with cardiac stereotypes and high-risk groups. Family history was found to affect perceptions of vulnerability by providing a context in which respondents interpret their own ill-health, and by shaping their ideas about their vulnerability to heart disease.

Chapter 9 showed that responses to chest pain cannot be understood without reference to respondents' illness biographies, which were found to influence their ideas about normality and to determine their ability to accommodate the symptom of chest pain into their everyday experience. Respondents with multiple health problems often had reduced expectations of future health and life expectancy and for them, chest pain was often regarded not as a devastating experience, but as just another health problem. In contrast, those who reported good general health were more likely to interpret their chest pain as out of the ordinary. Respondents with multiple health problems often found it difficult to sort out their chest pain from symptoms of other diseases, and rather than evoke a new disease, they tended to attribute their chest pain to a condition which had already been diagnosed. Multiple morbidity was commoner in the socio-economically deprived area, so

normalisation of chest pain and wrong attribution of symptoms were commoner in this group.

Chapter 10 argued that previous negative encounters with doctors could lead to a reluctance to present with chest pain. The quality of such encounters varied between the respondents and was determined by three factors: the degree of social alignment between doctor and respondent; the extent of the respondent's knowledge and degree of knowledge-sharing in the medical consultation; and the extent to which the patient conformed to a healthy lifestyle. People from the socio-economically deprived area were more likely to perceive that they had experienced negative encounters with their GPs. Women were more likely to report that they had not been taken seriously by their GPs. I suggested that the reluctance to present was particularly strong for chest pain because of the common perceived association between heart disease and blame.

In the next section of this chapter, I discuss the main overarching themes which resulted from the analysis: 'normalisation of chest pain', 'victim-blaming' and 'heart disease as a disease of men', and suggest the ways in which the conclusions relate to the known inequalities in service use. I then outline some limitations of the study method. Finally, I make some tentative recommendations for health promotion, health professionals and researchers.

11.1 Themes of the study

11.1.1 Normalisation of the symptom of chest pain

Responses to chest pain were influenced by whether or not the experience was interpreted as being out of the ordinary. The respondents judged the significance of their chest pain in relation to three criteria: their personal characteristics, such as their age, gender and socio-economic status; their previous experience of and future expectations of ill-health; and wider contextual factors, such as respondents' exposure to ill-health and whether there was heart disease in their families and wider social groups. The theme 'normalisation of chest

pain' recurred throughout the analysis, particularly in relation to perceived vulnerability to heart disease and previous illness experience.

The idea that responses to symptoms can only be fully understood by taking into account contextual factors is not new. For example, in relation to his study of the use of social networks for ante-natal care in Aberdeen, McKinlay (1973) highlighted the importance of 'reference groups' against which people judge their own experiences:

A major source of any individual's orientation and behaviour are the values and norms of the groups or social networks to which he relates himself – his reference groups. These values and norms apparently constitute the major anchorages in relation to which an individual's experience or self-identity is organised. (page 288)

Blaxter and Paterson, in their study of health attitudes and behaviour of working-class women in Aberdeen, identify the theme of 'normalisation of illness' as being important in relation to gender, age and socio-economic status. They state that an important factor underpinning women's attitudes to illness was, "*their conception of normal illnesses*", which the authors described as "*troubles which were or are common, the type of things that 'people like us' could expect to suffer*" (page 31). In addition to this general identification with poor health, Blaxter and Paterson found that their older respondents dismissed chronic symptoms as illness because they had become so "*used to their presence*" (page 31), and that women of all ages presented themselves as healthy if they believed that their symptoms related simply to being older or to being female. Blaxter and Paterson did not look in detail at the ways in which normalisation of ill-health affected illness behaviour, but they did provide some evidence that women tend to neglect illnesses which are regarded as 'normal' in relation to their low expectations of health.

Like Blaxter and Paterson, I found that when assessing the significance of their chest pain, respondents took into account their own personal characteristics such as age, gender and socio-economic status, as well as their illness biographies and their expectations of future health, and their degree of exposure to ill-health in members of their families and social groups. My analysis of normalisation of ill-health has extended the work of Blaxter and Paterson in several ways. First, whereas their study was based on interviews about general

experience of ill-health (including minor and chronic illness), my study focused on chest pain. It might have been predicted that contextual factors would be less influential in determining responses to a symptom such as chest pain, which is generally regarded as serious, but my study has demonstrated the importance of such factors. Second, because my study was concerned with a specific illness experience, it was able to examine in some depth the complex inter-relations between the process of normalisation of symptoms and perceived vulnerability to ill-health. Third, my study included men and women from a range of social backgrounds, and could therefore explore the relationships between normalisation of ill-health and gender and socio-economic status. Fourth, my study aimed to make explicit links between perceptions of chest pain and illness behaviour.

My study has suggested that there may, for some respondents, be a balance between normalising their chest pain (with respect to their age, gender or illness experience) and feeling vulnerability to heart disease. The balance between these two factors seems to vary depending on the socio-economic status and gender of the individual. The tendency to normalise chest pain was greater amongst respondents from the socio-economic deprived area, who often portrayed ill-health as being part of the 'wallpaper' of their lives. In contrast, for the more affluent people, episodes of illness often occurred against a background of good health. Perceived vulnerability to heart disease was also greater in people from the socio-economically deprived population and stemmed from the greater exposure to personal and family ill-health. With regard to gender, perceived vulnerability to heart disease was greater in men than women, but women often attributed their pain to stress, ageing or the menopause.

The complex balance between perceived vulnerability to heart disease and normalisation of ill-health means that it is difficult to make predictions of how people from different groups will actually behave in response to chest pain. Women's lack of perceived vulnerability to heart disease, coupled with their tendency to normalise their chest pain, might partially explain their reluctance to present with chest pain. Predictions of behaviour based on socio-economic status are even more complex because although people from the deprived area reported a greater vulnerability to heart disease (which might be expected to increase their tendency to present), they were also more likely to normalise their chest pain. In addition, members of this group, who often had extensive exposure to other health problems, were able to attribute their chest pain to other causes.

This analysis has confirmed the importance of social context and ideas of normality for the interpretation of chest pain; it has suggested that there may be a balance between 'perceived vulnerability' and 'normalisation', and it has argued that these factors may partly explain why women are less likely to present with chest pain than men. However, no firm conclusions can be reached about the relationship between illness behaviour and socio-economic status. That relationship is explored further in the next section, which discusses the theme of 'victim-blaming and demoralisation'.

11.1.2 Victim-blaming and demoralisation

'Victim-blaming and demoralisation' was a recurrent theme in this study. It arose in relation to the identification of cardiac stereotypes and high-risk groups, and in relation to previous experience of health-care. I demonstrated that the links between risk behaviour and heart disease were universally acknowledged by the respondents, and that they were recognised as important defining characteristics of cardiac stereotypes. Later in the thesis, I presented evidence that heart disease was associated by respondents with blame. Self-blame often led to feelings of demoralisation amongst respondents, and to a reported reluctance to present with chest pain.

Victim-blaming was first described by Crawford (1977) who argued that it is at the heart of an ideology which emphasises that individuals should take more responsibility for their own health. In the UK, a number of studies have provided evidence, not only for the widespread belief that health and illness are the responsibility of the individual, but also that the emphasis on individual responsibility (as opposed to environmental and structural factors) is stronger in people from lower social classes. For example, Blaxter referring to the Health and Lifestyle Survey (Blaxter 1990), states:

It can be concluded, on the basis of this one large-scale survey, at least that the lessons of public policy and health education 'you are responsible for your health' have been accepted [...] and it is those with higher incomes or better education who are likely to be aware of the evidence of sociology and social epidemiology which stresses structural and environmental factors. (Blaxter 1993) (page 126)

In reviewing the evidence in this area, Blaxter (1993) concluded: *“Those who are in the lowest social classes, or have the least education are most likely to confine their explanations [of health] to behavioural causes”* (page 124).

More recently, researchers have made the link between victim-blaming and illness behaviour. Butler and colleagues (1998), in a qualitative interview study of patients’ perceptions of doctors’ advice to give up smoking, found that for some patients, who were not ready to give up smoking, advice from their GP to quit could lead to feelings of guilt and to changes in their health-seeking behaviour. The authors state: *“Two subjects gave accounts of putting their health in danger by not attending for needed medical help because they felt that their doctor would talk to them about stopping smoking”* (page 1880). Despite using a purposive sample to recruit men and women from a range of social backgrounds, that study did not draw any conclusions relating to gender or social-class variations in illness behaviour.

My study has confirmed the existence of the culture of victim-blaming and self-blame, and like the Health and Lifestyle Survey (Blaxter 1990), it found that self-blame was stronger in people of lower socio-economic status. It has also provided new evidence that self-blame can lead to an inappropriate reluctance to seek medical care for chest pain, and that this reluctance is associated with socio-economic deprivation.

11.1.3 Heart disease: a ‘male disease’

This study provides evidence for gender differences in the ways in which men and women think about and respond to chest pain. Not only did men regard themselves as more vulnerable to heart disease than did women, but there was a general perception that women are at low risk. Neither men or women stressed the scientifically accepted explanation for this difference (that women are protected at least until the age of the menopause by endogenous oestrogen): instead, they emphasised the association between CHD risk and their social roles. I suggested that as well as women’s perceived invulnerability to heart disease, their reluctance to present with chest pain related to their commitment to the role of family health custodian.

Over the past decade, there has been a great deal of research in the UK and the US into gender variations in uptake of cardiology services (see chapter 3). A commonly cited explanation for the observation that women are less likely to undergo cardiological investigations and treatments is that heart disease is perceived by lay people and health professionals as a disease of men. For example, Sharp (1994) states:

CHD is perceived as a male disease, both by the public and by health professionals. The image is reinforced by the media, health education, research and the medical press. This has several potential implications. Women may be less likely to [...] attribute symptoms to CHD. Health professionals may be less likely to offer women advice on CHD prevention and to pick up symptoms at an early stage. (page 25)

Although the assertion that women are perceived as being at low risk of heart disease, pervades the research literature, there is very little evidence to support it: most studies which have explored perceptions of heart disease have used exclusively female samples. One exception is a study by Emslie and colleagues (2001), which involved interviewing men and women about their perceptions of family history of heart disease and their ideas about coronary candidacy. That study is particularly relevant to mine because it was carried out in the west of Scotland, it used a similar population to mine (men and women aged 41-55 from a range of social backgrounds), and it was carried out at approximately the same time as my study. It confirmed that coronary candidates are generally perceived as people who smoke, who are sedentary and who eat a poor diet, but also showed that *“whenever respondents talked about specific ‘coronary candidates’, they were invariably talking about men”* (page 20).

My study, like that of Emslie and colleagues (2001), found that heart disease was generally perceived by men and women as a male disease: reported cardiac stereotypes were all either explicitly or implicitly male. However, my data suggested one exception to this general pattern: 6 women from the socially deprived area perceived that women are at greater risk of CHD than men. The stated reason for that perception was that women are under greater stress resulting from their caring roles. Interestingly, the respondents who believed that men are at greater risk also cited the importance of stress arising from social roles or from individuals' inability to deal with stress. Although my analysis supports the

general assertion that heart disease is perceived to be a disease of men, it has also suggested that the true picture of lay perceptions may be more complicated.

I have stated above that, with the exception of the work by Emslie and colleagues, there is little empirical evidence to support the assertion that heart disease is generally regarded as a male disease. The links between women's perceived vulnerability to heart disease and behavioural responses to chest pain is even less well documented. Previous researchers, such as Hibbard and Pope (1986), have examined the possible explanations for gender variations in general patterns of help-seeking behaviour. My study, focussing specifically on chest pain, concluded that women were less likely than men to present to a doctor, but that the reasons for this difference are not straightforward. First, most of the women did perceive heart disease to be a disease of men. Second, many women normalised their chest pain, regarding it as a function of their increasing age, of the general stress of their lives or simply of 'being female'. Third, they attributed the pain to other causes, such as stress or the menopause. Fourth, they were less likely to discuss their pain with family members, and their lay consultations often did not result in them seeking medical care. Finally, they often expressed a reluctance to present with chest pain because they were concerned that by presenting, they would be forced to interrupt their caring roles.

11.2 The study methods

11.2.1 Combining qualitative and quantitative methods

Two aspects of the study method require further discussion: the complex relationship between the quantitative and qualitative elements of the study, and the decision to impose a preconceived framework of 'gender and socio-economic status' on the analysis of the interview data. These two issues will be discussed in turn.

The study's objectives were to describe the perceptions of, and behaviour in response to chest pain, of a sample of men and women living in Glasgow; to examine the relationship between these perceptions and behaviour and their gender and socio-economic status; and to offer some explanation for the known gender and socio-economic variations in rates of

uptake of cardiology services. The first two objectives have been fulfilled and form the basis of chapters 7-10. The third objective has proved to be more problematic.

The study began from the assumption, based on previous research, that there are gender and socio-economic inequities in the uptake of cardiology services. It was designed to explore the possibility that these inequities might arise, at least in part, from variations in lay perceptions of, and illness behaviour in response to chest pain. With regard to gender variations, the case-note study found that women were less likely than men to present with chest pain, and I concluded that gender variation in patterns of GP presentation may contribute to inequities in uptake of services. The qualitative study then described the possible explanations for the relative reluctance of women to present (section 11.2.3).

The case-note retrieval study (Richards, McConnachie *et al.* 2000) did not demonstrate that people from the socio-economically deprived area were less likely to present with chest pain. In fact, a higher proportion of this group presented, and I therefore concluded that illness behaviour is not likely to contribute to socio-economic variations in uptake of services. The picture is further complicated by the results of the qualitative analysis presented in this thesis. Although I have stressed that the decision to present involves a complex interplay of factors (including perceived vulnerability; illness experience, experience with health professionals, and lay care and self-care), my overall conclusion is that people from the deprived area are less likely to present with chest pain. This conclusion is, on the face of it, contrary to the findings of my quantitative study.

There are several explanations for this apparent contradiction. First, the selection criteria for the case-note study and the qualitative study were not the same. The case-note study included survey respondents with chest pain (non-exertional chest pain and Rose angina) and some of these respondents will have experienced chest pain resulting from causes other than heart disease. The interview sample was restricted to respondents with Rose angina. I concluded in the case-note study that the greater tendency to present with chest pain in the deprived area might possibly reflect the general higher use of primary care services in deprived areas (Carr-Hill, Rice *et al.* 1996), and it is likely, given its stricter inclusion criteria, that the interview study gives a truer impression of the way that people respond to angina. Second, although in the interviews, I attempted to ascertain whether an

actual presentation had been made, I was less concerned with that than with understanding the factors underlying the decision-making process. Third, it is possible that respondents stated intentions to present and their recall of whether they had presented may not be an accurate account of what was actually done. Fourth, in some cases, although a respondent may have mentioned 'chest discomfort' to their GP, the GP may have interpreted and recorded the symptom as chest pain.

The difficulty of reconciling the (quantitative) case-note findings with the (qualitative) interview findings begs some questions about the value and pitfalls of combining qualitative and quantitative methods. The benefits of mixing methods in health services research have been well rehearsed (Barbour 1999), but less attention has been focussed on the possibility that quantitative and qualitative data can give apparently contradictory results. Barbour (1998) considers the problem of contradictory findings in relation to mixing different qualitative methods, and argues that when contradictory findings are obtained, this can lead to '*hierarchies of evidence*' (page 356). I conjecture that in health services research, when qualitative and quantitative studies yield contradictory results, it is the quantitative evidence which is often assumed to be more valid. One of the recognised advantages of using a mixed-method approach is to identify areas which require further investigation. In this study, three questions have arisen from the apparent contradiction in the quantitative and qualitative results: "To what extent does the patient's recall of presentation accord with whether he or she actually presented?"; "To what extent does the patient's recollection that he or she presented with chest pain accord with GP records of the presentation?"; and "Do patterns of presentation for all chest pain differ from patterns of presentation for angina?".

11.2.2 Analysis by gender and socio-economic status

This study was designed to explore the possibility that gender and socio-economic variations in uptake of cardiology services arise from variations in lay perceptions of and responses to chest pain. The sample was selected with this aim in mind and the analysis was carried out within a preconceived framework. Throughout the analysis, I was 'looking for' variations in perceptions and behaviour which might be related to gender and socio-economic status. This directed approach to analysis is common in health services research,

and is often designed to answer specific questions. It also has the advantage that the analysis is focussed on the main research question. However in relation to my study, I recognised a significant drawback to this approach: although my analysis adhered to the general principles of grounded theory (chapter 6), the preconceived conceptual framework of 'gender and socio-economic status' meant that the analysis was not strictly driven by the data, and it tended to preclude the use of alternative frameworks.

The most obvious alternative framework for the analysis would have been to compare respondents who had presented with chest pain with those who had not. However, this analytic framework would not have worked well with my sample because of the problem of not being sure whether a presentation had in fact taken place. For example, some respondents gave no clear answer to the question of whether or not they had presented; some could not remember; some said that they had presented with 'discomfort' or 'tightness', but not with pain; and others had mentioned their chest pain 'in passing', while attending the GP for a different problem. In order to apply a framework of 'presentation vs. non-presentation', it would have been better to sample with this issue in mind - perhaps by using a preliminary screening questionnaire which asked respondents whether or not they had presented.

A second potentially useful analytic framework is one which took into account the clinical diagnosis of the chest pain. However, I have demonstrated that respondents' descriptions of chest pain varied considerably, and often bore little relationship to the clinical diagnosis. In order to look more closely at the ways in which responses varied with clinical diagnosis, it would have been better to recruit the sample from a cardiology clinic (after a reliable diagnosis had been made), and to make a retrospective comparison of respondents' initial reactions to chest pain. Although I acknowledge that the data could be analysed in other ways, I feel that the decision to concentrate on gender and social class was justified in relation to this study's stated objectives, and because a boundless analysis with no or multiple preconceived categories may have led to an unmanageable analysis or to a superficial understanding of the issues.

11.3 Implications and recommendations of the study

The main reasons stated by respondents for not presenting with their chest pain were lack of perceived vulnerability to heart disease; normalisation of symptoms in relation to age, gender and expectations of health; fear of chastisement by doctors; and the constraints of social roles and responsibilities. In this section, I consider whether, from the main conclusions of the study, there are any recommendations which can be made to those involved in health promotion; to health professionals and for future research.

11.3.1 Health promotion

There are essentially two approaches to health promotion: that which places responsibility for health on the individual and attempts to modify behaviour through using health education, and that which emphasises the influence of social and structural constraints. The former approach, which was dominant throughout the 1980s, is illustrated by a quotation from a Department of Health publication (1976), quoted by Parish (1995):

Many of the current major problems in prevention are related less to man's outside environment than to his own behaviour; what might be termed our lifestyle. For example, the determination of many to smoke cigarettes in the face of the evidence that it is harmful to health and may well kill them. (page 14)

It has been suggested by Davison and Davey-Smith that, even in the early 1990s, official health policy downgraded the "*social and economic contexts of lifestyle and behaviour in disease causation*" (1995).

It has been argued that since the election of the New Labour government in 1997, the individualist approach has been replaced with one which "*locates root causes [of health and ill-health] in social conditions such as income levels, employment opportunities, quality of housing and the environment*" (Naidoo & Wills 1994) (page 137). And

researchers have made a powerful case for a broader approach to health promotion, incorporating social and political influences on health (Parish 1995), (Graham 1990).

Despite this shift in the ideology of health promotion, it was clear that my respondents had been powerfully influenced by the individualist message, which may explain why respondents generally felt to blame for their own health problems. This lasting influence may relate to a 'cultural lag' (Pill & Stott 1982) between the officially sanctioned version of illness causation (individual behaviour) in the 1980s and lay ideas in the 1990s. Self-blame may have been particularly relevant to chest pain, because of the association between chest pain and heart disease, which is widely believed to be a blameworthy condition.

Respondents' belief that that they were to blame for their heart disease because of unhealthy behaviour often led to a reluctance to present to a doctor with chest pain. Two factors were found to underpin this reluctance. First, respondents who took part in 'unhealthy lifestyles' felt that they were unworthy of medical care. Second, they expressed a fear that they would be chastised for their risk behaviours by doctors. The negative effect of health promotion on illness behaviour seemed to be greater in the socio-economically deprived area where respondents were more likely to report risk behaviours.

There is a clear association between socio-economic deprivation and poor health in the UK (Black, Morris *et al.* 1980), (Benzeval, Judge *et al.* 1995). Recently, Watt and Ecob (2000) demonstrated widening differences in life expectancy between Glasgow and Edinburgh. These authors state that precise explanations of this observation are not possible but that it is likely to be explained by the cities' "*consistently and markedly contrasting socio-economic profiles*" (page 330). At the same time, it has been demonstrated that in Scotland, up to 50% of the decline in coronary mortality rates in Scotland between 1975 and 1994 can be attributed to clinical interventions (Capewell, Morrison *et al.* 1999).

This study has raised the possibility that the lifestylist message might be more likely to lead to demoralisation and reluctance to present with chest pain in deprived populations. If this is the case, it could theoretically lead to poorer access to cardiac interventions and, subsequently, to less favourable CHD outcomes. It is possible therefore that by fostering

reluctance amongst some groups to present with chest pain, health promotion may have inadvertently contributed to increases in socio-economic variations in CHD mortality. Davison and Davey-Smith (1995) have suggested that health promotion "*represents a potential weapon in the battle against socio-economic inequalities in health*" (page 99). This study suggests that in some circumstances, by fostering a reluctance amongst socially deprived groups to present with new symptoms, it might contribute to socio-economic inequalities in health.

Health promoters have increasingly acknowledged the structural constraints to behavioural change. There are several examples in Glasgow of this ideology being translated into practice, such as a campaign to improve the health of women by taking into account the links between women's health and their social roles (Laughlin 1998). Laughlin states that the main aim of that campaign was to "*replace the medical model with a social one as the dominant framework for healthcare and health promotion*" (page 221). In relation to heart disease, a recently published health promotion leaflet which aims to educate women about heart disease emphasises the behavioural risk factors but also acknowledges the adverse effects of 'poor circumstances' on heart disease risk (Greater Glasgow Health Board 1995). My study suggests that this de-emphasis on individual behaviour as a cause of CHD and a greater emphasis on the wider causes of ill-health might help to ensure that people with chest pain are not deterred from seeking medical care.

As regards gender, there has been a recent recognition amongst charitable foundations and health promotion departments that health promotion for heart disease should target women (Sharp 1994a), (Greater Glasgow Health Board 1995). A recent British Heart Foundation bill-board which read "*Britain's no.1 Ladykiller Isn't A Man*" attempted to raise the profile of CHD in women. As well as emphasising that women are at risk of heart disease, such campaigns have urged women to seek medical care for chest pain. However, this study found that women's reasons for not presenting involved factors other than their perceived vulnerability, such as their propensity for self-care and lay referral, and the practical and psychological restraints of their roles as custodians of family health. Health promoters should educate men and women about these general influences on women's health and health behaviour, as well as concentrating on specific diseases, such as CHD.

11.3.2 General practitioners

I have argued above for a de-emphasis of the individualist health promotion message. However, it is likely, because of 'cultural lag', that it will take time for the individualist message to recede from the consciousness and narratives of lay people, and to be replaced by a model which acknowledges structural constraints and social context. Meanwhile, it may be that the best way to de-emphasise self-blame is for health professionals such as doctors and practice nurses to be sensitive to these issues.

Health promotion has long been recognised as one of the four central tasks of the general practice consultation (Stott & Davis 1979), and since the late 1980s, individual behaviour change and the surveillance of health-related behaviour have been integrated into the formal workload of GPs (Davison & Davey-Smith 1995). There is some evidence that health promotion within the consultation can change behaviour. For example, Silagy and Ketteridge (1996) showed that 2% of smokers will quit if advised to do so by a doctor. However, little is known about the possible negative effects of doctors' advice to change behaviour. A recent qualitative study of patients' perceptions of doctors advice to quit smoking did identify some negative effects: not only did some of the respondents become annoyed at repeated suggestion by doctors to quit smoking but in some cases the doctor patient relationship was damaged and respondents were deterred from seeking medical care. That study found that "*[health promotion] interventions that respondents found acceptable took account of their receptiveness; were conveyed in a respectful tone; avoided preaching; showed support and caring; and attempted to understand them as a unique individual*" (page 1880).

My study also demonstrated that repeated allusion by GPs to risk behaviours (such as smoking, alcohol and poor diet) could lead to self-blame and demoralisation amongst respondents and a reluctance to present with chest pain. In those cases, health promotion in the consultation seemed to be undermining its curative function. This phenomenon may occur more in areas of social deprivation, because of the higher levels of risk behaviour and higher prevalence of chest pain. My study, like that of Butler and colleagues (Butler, Pill *et al.* 1998), has suggested that in order to avert this problem, GPs carrying out health

promotion in socially deprived areas should be sensitive to the social and cultural contexts of their patients and the barriers to the adoption of healthier lifestyles.

11.3.3 Future research

More research is needed into illness behaviour. Most of the theoretical models of illness behaviour which are still in use today emerged from the work of sociologists and psychologists working in the 1960s and 1970s. I have indicated in the above discussion that illness behaviour is likely to be influenced by the prevailing political climate, and it is likely that these models are limited not only because they tend to be simplistic but because they are outdated. In order to understand illness behaviour in contemporary society, it is necessary to carry out further detailed qualitative work, such as that carried out by Blaxter and Paterson in Scotland (1982a) and Pill and Stott in Wales (1982). Such studies are needed to explore the changes in beliefs about health, illness and illness behaviour which have paralleled the shift in the political climate in the UK since the 1980s. They should, like this study, incorporate gender and socio-economic status into the sampling strategy: socio-economic status, because of the paucity of ethnographic studies which include affluent people; gender, because of the increasing awareness of gender inequities in health and illness behaviour.

Although contemporary qualitative research into general illness behaviour would provide new theoretical insights, I have suggested that illness behaviour is partly dependent on the disease or symptom in question. For example, the construction of heart disease as blameworthy is crucial to understanding responses. Therefore, in addition to exploring general theories of illness behaviour, future studies should acknowledge that responses to a condition are likely to be influenced by the ways in which that particular disease is socially constructed.

Further research is also needed to address the ways in which illness behaviour is affected by the experience of multiple health problems and by previous health-care encounters. My study has suggested a number of ways in which co-morbidity can affect illness behaviour, but it would be useful to conduct further quantitative and qualitative work focussing solely on this issue, particularly on the relationship between previous illness experience and help-

seeking for new symptoms. A central research focus of general practice research has been the process and immediate outcomes of the consultation, but with a few notable exceptions (Rogers, Hassell *et al.* 1999c), there has been little research exploring the effect of the consultation on subsequent illness behaviour.

Finally, in addition to these general topics, further research is required to improve our understanding of variations in uptake of secondary cardiology services. Existing studies describe the processes occurring at secondary care level (Petticrew, Jones *et al.* 1993), (Payne & Saul 1997), and this study has provided a detailed analysis of the factors which affect patient perceptions of chest pain and their illness behaviour. The 'missing link' would now appear to be the lack of research into general practice referral patterns for chest pain. Quantitative studies which measure variations in referral rates, and qualitative studies which investigate general practitioners' beliefs and behaviours, are now required to illuminate the persisting inequalities in access to secondary cardiology services.

Appendices

- Appendix 1** **Published results of survey and case-note study**
- Appendix 2** **Community Health Survey questionnaire**
- Appendix 3** **Letter to interview participants**
- Appendix 4** **Interview schedule**
- Appendix 5** **Coding schedule**
- Appendix 6** **Published paper on reflexivity**

Appendix 2

Community Health Survey questionnaire



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COMMUNITY HEALTH STUDY

Please answer all the questions in this questionnaire. The questionnaire should take no more than 20 minutes to complete. All replies will remain confidential to the research team at the Department of General Practice, Glasgow University. Thank you for your cooperation.

Personal History

1 (a) Sex (tick one box)

Male Female

(b) Date of Birth

D D M M Y Y

(c) Where were you born?

Town/Place

County

Country

FOR OFFICE USE ONLY
Code

2 Please tick the box showing your present marital status

Married Cohabiting Single Widowed Divorced Separated

3 (a) What is the highest level of education you have completed? (tick one box)

- University Degree
 Other professional or technical qualification or diploma after leaving school
 Secondary School

(b) How many years altogether have you gone to school or studied full time from the age of 5 years? years

4 (a) Please tick the appropriate box about your employment situation

- In a full time job
 In a part time job
 Unemployed, seeking work. If unemployed and seeking work, for how long have you been unemployed? years months
 Unemployed because sick or disabled
 Housewife/homemaker
 Wholly retired from employment
 Full time student

4 (b) Please give full and precise details of your and your husband/wife/partner's occupation
(If unemployed now, give details of last job)

Your occupation

Description of your work

Husband/Wife/Partner's occupation

Description of his/her work

(c) What is your and your husband/wife/partner's employment status? (If unemployed now, give details of last job)

You	Husband/Wife/Partner	
<input type="checkbox"/>	<input type="checkbox"/>	Employee not supervising other employees
<input type="checkbox"/>	<input type="checkbox"/>	Employee supervising other employees
<input type="checkbox"/>	<input type="checkbox"/>	Self employed not employing others
<input type="checkbox"/>	<input type="checkbox"/>	Self employed employing others
	<input type="checkbox"/>	Does not apply to me

5 How do you and your household occupy your accommodation?

As an owner-occupier (including purchase by mortgage)

By renting or rent free, or by lease from local authority or from a housing association

By renting or rent free, from a private landlord or in some other way

Family History

6 Did your mother or father have heart disease before they were 60 years old? Yes No Don't Know

7 How many brothers and sisters did you have in your family? (not counting yourself)

Physical Activities

8 Do you usually walk and/or cycle during your activities each day? (tick two boxes if you want)

No

Walk Total time walked each day minutes

Cycle Total time cycled each day minutes

9 (a) How many hours a day do you do paid work? hours a day

(b) How many hours a day do you do housework? hours a day

(c) How many days a week do you do paid work? days a week

(d) How many days a week do you do housework? days a week

10 (a) **When working (including housework), for how long are you physically very active, moderately active, or inactive on average a week?**

Very active (for example, heavy lifting or carrying, hurried walking, going up stairs or ladders, digging, strenuous exercise, heavy housework)

hours a week

Moderately active (for example, lifting or carrying, moderate walking, light housework, shopping, painting, decorating)

hours a week

Inactive (for example, sitting, standing, light arm movements, unhurried walking, driving)

hours a week

(b) **When working (including housework) how often are you physically active for at least 20 minutes during which time you become short of breath and perspire? (tick one box)**

More than 3 times a week

Less than once a week

2-3 times a week

Never

Once a week

11 (a) **During your non-working time (including going to and from work), for how long are you physically very active, moderately active or inactive on average a week?**

Very active (for example, competitive sports (football, hockey, squash, badminton), hill walking, bicycling, swimming, running, aerobics, windsurfing, heavy gardening)

hours a week

Moderately active (for example, moderate walking, golf, light gardening, cricket, dancing, bowls, playing pool, shopping, sailing, taking a shower or bath, getting dressed)

hours a week

Inactive (for example, sitting, standing, watching TV, listening to music, cooking, visiting pub, drinking, eating, piano playing, card playing, driving. Do not count time in bed.)

hours a week

(b) **During your non-working time, how often are you physically active for at least 20 minutes during which time you become short of breath and perspire? (tick one box)**

More than 3 times a week

2-3 times a week

Once a week

Less than once a week

Never

12 (a) **Would you say that over the past year your level of physical activity has**

increased? Stayed the same? Decreased?

(b) **If it has changed, for how many months has it been at its current level?**

months

13 **How many hours a day do you usually spend in bed?**

On work days

hours

On non-work days

hours

Cigarette Smoking

14 (a) Do you smoke cigarettes now? If 'No' go to question 15

Yes regularly No Occasionally (usually less than one a day)

(b) On average, about how many cigarettes do you now smoke a day? cigarettes a day

(c) On average, on how many days a week do you smoke cigarettes? days a week

15 (a) Did you ever smoke cigarettes? If 'No' go to question 17

Yes regularly No Occasionally (usually less than one a day)

(b) How old were you when you began to smoke cigarettes? years old

(c) What is the maximum number of cigarettes you ever smoked a day for as long as a year?

cigarettes a day

(d) How long ago did you stop smoking cigarettes?

years ago

months ago

days ago

(e) Have you ever tried to give up smoking? If 'No' go to question 17 Yes No

(f) On the last occasion you tried to give up, for how long did you succeed?

years

months

days

16 Why did you try to give up smoking? (Tick yes or no for each question. You can have one or more 'yes' answers.)

Yes No

Because of my cough/phlegm

Because I was breathless

Because I had heart disease or was worried that I might have heart disease

Because smoking is bad for me

Because of the illness or death of a friend or relative

Because the doctor or clinic nurse told me

To save money

Other reason (please specify)

17 Does your spouse/person you live close to, smoke?

Yes No Does not apply to me

Alcoholic drinks

18 (a) Have you ever taken alcoholic drinks? If 'No' go to question 20 Yes No

(b) Do you ever take alcoholic drinks at present? Yes No

19 (a) Think back carefully over the last seven days. Please write in exactly what alcoholic drinks you have consumed on each day during the past week. Try to remember where you were and who you were with on each day. This may help you to remember what you have had to drink. For each day, write in how much you had to drink.

	Pints of non-alcoholic beer, lager, shandy, etc	Pints of low-alcoholic beer, lager, shandy, etc	Pints of beer, lager, shandy, etc	Single glasses of spirits, etc	Single glasses of wine, etc	FOR OFFICE USE ONLY Code
Monday	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Tuesday	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Wednesday	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Thursday	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Friday	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Saturday	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Sunday	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

(b) Would you say that last week was fairly typical of what you usually have to drink in one week? Yes No

(c) If last week was not typical, would you normally drink more or less in a week? more less

Diet

20 What kind of bread do you usually eat? (tick one box)

- White
- Brown, granary, wheatmeal
- Wholemeal
- Other (please specify)
- No usual type
- Do not know
- Do not eat bread

21 What do you usually spread on bread? (tick one box)

- | | |
|---|--|
| <input type="checkbox"/> Butter | <input type="checkbox"/> Low fat spread |
| <input type="checkbox"/> Hard/block margarine | <input type="checkbox"/> No usual type |
| <input type="checkbox"/> Soft margarine | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Reduced fat spread | <input type="checkbox"/> Do not spread any of these. Go to question 23 |

22 How do you spread the fat? (tick one box)

- Thickly Medium Thinly

23 What kind of fat do you usually use for frying? (tick one box)

- | | |
|--|--|
| <input type="checkbox"/> Butter | <input type="checkbox"/> Margarine |
| <input type="checkbox"/> Lard/dripping | <input type="checkbox"/> Other (please specify) <input type="text"/> |
| <input type="checkbox"/> Vegetable oil | <input type="checkbox"/> Don't eat fried food |
| <input type="checkbox"/> Solid vegetable fat | |

24 How much do you usually eat in a day? (tick one box in each line)

	6 or more	4-5	2-3	1	less than 1
Slices of bread/rolls	<input type="checkbox"/>				
Plain biscuits (digestives etc)	<input type="checkbox"/>				
Sweet biscuits including chocolate biscuits	<input type="checkbox"/>				
Cakes, scones, sweet pies and pastries	<input type="checkbox"/>				

25 What kind of milk do you usually use for drinks, in tea or coffee and on cereals etc? (tick one box)

- | | |
|--|--|
| <input type="checkbox"/> Whole milk | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Semi-skimmed | <input type="checkbox"/> Other (please specify) <input type="text"/> |
| <input type="checkbox"/> Skimmed | <input type="checkbox"/> Do not drink milk |
| <input type="checkbox"/> No usual type | |

26 How much milk do you use each day e.g. on breakfast cereals, in tea/coffee, cooked foods (custard etc)?

Don't count what other family members use, just what you use. (tick one box)

- | | |
|--|---|
| <input type="checkbox"/> More than 2 pints | <input type="checkbox"/> Between 1/2 and 1 pint |
| <input type="checkbox"/> Between 1 1/2 and 2 pints | <input type="checkbox"/> Less than 1/2 pint |
| <input type="checkbox"/> Between 1 and 1 1/2 pints | <input type="checkbox"/> None |

27 How many cups do you drink in a day of:

	Number of Cups	How many spoons of sugar in each cup?
Tea?	<input type="text"/>	<input type="text"/>
Coffee?	<input type="text"/>	<input type="text"/>

28 **At the table do you** (tick one box)

- Generally add salt to food without tasting first?
 Taste food but only occasionally add salt?
 Taste food and then generally add salt?
 Rarely or never add salt at table?

29 **Which type of breakfast cereal do you normally use?** (tick one box)

- High fibre e.g. All Bran, Branflakes, Shredded Wheat, Muesli, Porridge, Weetabix
 Other e.g. Cornflakes, Rice Krispies, Special K, Sugar Puffs, Honey Snacks
 No usual type
 Do not eat breakfast cereal

30 **How often do you eat these foods?**
(tick one box on each line)

	<i>Times per Day</i>				<i>Times per Week</i>			<i>Times per Month</i>	
	6+	4-5	2-3	once	5-6	2-4	once	1-3	less than once
Pure fruit juice	<input type="checkbox"/>								
Breakfast cereal	<input type="checkbox"/>								
Fresh fruit	<input type="checkbox"/>								
Cooked green vegetables (fresh or frozen)	<input type="checkbox"/>								
Cooked root vegetables (fresh or frozen)	<input type="checkbox"/>								
Raw vegetables or salad (including tomatoes)	<input type="checkbox"/>								
Chips	<input type="checkbox"/>								
Potatoes, pasta, rice	<input type="checkbox"/>								
Meat	<input type="checkbox"/>								
Sausages/meat pies/burgers	<input type="checkbox"/>								
Poultry	<input type="checkbox"/>								
White fish	<input type="checkbox"/>								
Oil rich fish (salmon, herring, tuna, pilchards etc)	<input type="checkbox"/>								
Other types of fish (including shell fish)	<input type="checkbox"/>								
Cheese	<input type="checkbox"/>								
Beans or pulses	<input type="checkbox"/>								
Sweets, chocolates	<input type="checkbox"/>								
Ice cream	<input type="checkbox"/>								
Crisps, savoury snacks	<input type="checkbox"/>								
Soft/ fizzy drinks	<input type="checkbox"/>								
Cakes, scones, sweet pies or pastries	<input type="checkbox"/>								
Plain biscuits (digestives etc)	<input type="checkbox"/>								
Food fried at home	<input type="checkbox"/>								
Food fried 'away from home' e.g. chip shops	<input type="checkbox"/>								

31 Are you on a special diet?

- No
- Slimming diet, prescribed by the doctor
- Slimming diet you decided for yourself
- Diabetic diet
- Cholesterol lowering diet
- Other medical diet
- Vegetarian diet
- Vegan diet

Medical History

- 32 (a) Over the last year, have you had your blood pressure measured?** Yes No
- (b) Over the last year, have you had your blood tested for cholesterol?** Yes No
- 33 (a) Are you now taking any medication for high blood pressure?** Yes No
- (b) Are you now taking any medication for high cholesterol?** Yes No
- 34 (a) Are you now taking aspirin regularly? If 'No' go to question 35** Yes No
- (b) Is it for your heart?** Yes No Don't Know
- (c) If it is for your heart, why did you start taking it?**
- The doctor told you to take it
 - You decided for yourself
 - Other reason, please give details
- 35 (a) Are you regularly taking any other medication at present?** Yes No

(b) If 'Yes', please write the name of the medicine(s) and what you are taking it for (if you know).

(Please include all pills, bottles, tablets, inhalers (puffers), injections etc)

.....

.....

.....

.....

.....

.....

Symptoms

36 (a) Have you ever had any pain or discomfort in your chest?

Please tick 'Yes' if you have ever had any chest pain or discomfort, whatever you think it may be due to, or, if 'No' go to question 38

Yes No

(b) Do you get this pain or discomfort when you walk uphill or hurry?

Yes No

(c) Do you get it when you walk at an ordinary pace on the level? If 'No' to both 36(b) and (c), go to question 36(g)

Yes No

(d) When you get any pain or discomfort in your chest, what do you do?

Stop Slow Down Continue at same pace

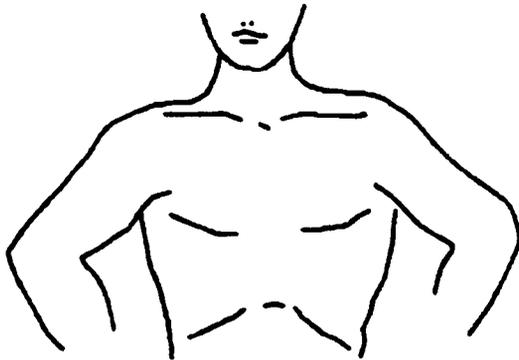
(e) Does it go away when you stand still? If 'No' go to question 37(g)

Yes No

(f) If 'Yes', how soon?

10 minutes or less More than 10 minutes

(g) Where do you get this pain or discomfort? Mark the places with X on the diagram



(h) Have you ever told a doctor about this pain or discomfort? If 'No,' go to question 37

Yes No

(i) What did the doctor say it was?

<input type="checkbox"/> Heart or angina	<input type="checkbox"/> Nerves or stress
<input type="checkbox"/> Stomach or indigestion	<input type="checkbox"/> Other
<input type="checkbox"/> Muscle, bone or joints	<input type="checkbox"/> Did not say

37 (a) Have you ever had a severe pain across the front of your chest lasting for half an hour or more? If 'No' go to question 38

Yes

No

(b) Have you ever told a doctor about this severe pain? If 'No' go to question 38

Yes

No

(c) What did the doctor say it was? (tick one box)

Heart attack or myocardial infection

Angina or heart cramp

Stomach or indigestion

Muscle bones or joints

Nerves or stress

Other

Did not say

38 Has a doctor ever told you that you have now, or once had any of these? (tick 'Yes' or 'No' for each of them)

Angina Yes No

Coronary artery bypass graft (CABG) Yes No

Heart attack (or coronary thrombosis or myocardial infarction) Yes No

High blood pressure Yes No

Diabetes Yes No

Stroke Yes No

High cholesterol Yes No

39 (a) Do you get short of breath when hurrying on level ground or walking up a slight hill?

Yes

No

(b) Do you get short of breath walking with other people of your own age on level ground?

Yes

No

(c) Do you have to stop for breath when walking at your own pace on level ground?

Yes

No

(d) Do you get short of breath when washing or dressing?

Yes

No

(e) Are you ever wakened from sleep by breathlessness?

Yes

No

The last section is for Women only.

Men please go to the instruction at the end of the questionnaire.

Women Only

40 (a) Have you ever been on the contraceptive pill? If 'No' go to question 41

Yes

No

If 'Yes', for how many years?

years

(b) Are you on the contraceptive pill now?

Yes

No

If 'No', how long ago did you stop?

years months

41 (a) Are you still having periods (menstruating)?

1. yes, usual natural periods

2. yes, but irregularly

3. yes, but only because I am having hormones (HRT)

4. no

If you ticked box 1 or 2, now go to question 41(d)

(b) How old were you when you stopped having normal periods? years old

(c) Was this because of a hysterectomy (operation to remove the womb)?

Yes

No

(d) Have you ever taken hormone replacement therapy (HRT)?

Yes

No

If 'No' you have completed the questionnaire. Please go to the instruction at the end.

(e) How old were you when you began to take it? years old

(f) For how many years did you/have you taken it? years

(g) Are you on hormone replacement therapy (HRT) now? Yes No

(h) If 'No' how long ago did you stop taking it? years ago

Thank you for your cooperation

Please return the completed questionnaire in the reply paid envelope provided to:

Dr Helen Richards
Department of General Practice
Woodside Health Centre
Barr Street
Glasgow
G20 7LR
Tel: 0141 332 8118

Appendix 3

Letter to interview participants

Letter to participants

Dear Participant,

Community Health Study

In May of last year I wrote to you asking you to complete the Community Health Study questionnaire. Thank you very much for returning it, the response rate was good and the results are currently being analysed.

The next stage of the study involves carrying out interviews with people about the way they think about medical symptoms, especially chest pain. Before doing the actual interviews, I plan to carry out a few informal discussions on this subject with a range of different people, which will enable me to design the plan for the interview study proper.

Your name has been randomly selected those who stated on the questionnaire that they had at some time had the symptom of chest pain and I am writing to ask whether you would consider taking part in a short discussion.

For this discussions, I am interested in your views and feelings, no specialist knowledge is needed. I would like to speak to you whether or not you have had a recent bout of ill health because I am interested in getting a broad range of opinions.

The interview will be carried out by myself at a time and place convenient to you (in most cases, we would do the interview at your home). It will last for about half an hour and all information will remain confidential to the research team.

I should be grateful if you would consider taking part. Please would you let me know by completing the tear-off slip below and returning it to me in the reply-paid envelope provided. If you agree, I will contact you by phone to arrange a time.

If you have any questions regarding the study, please feel free to contact me at the address below.

Yours sincerely

Dr Helen Richards

.....

Name.....Telephone.....

I would/would not be interested in taking part in a short discussion

Appendix 4

Interview schedule

Perceptions of chest pain: interview schedule

Introductory questions

1 Could you tell me a little bit about yourself?

Who makes up the household?/the family?

What you do for a living?/how do you spend your time?

General health questions

2 Description of health

How would you describe your general health?

What serious illnesses have you had in your life?

What minor illnesses have you had lately?

3 Actions in relation to general health

When you are unwell, (modify according to 2), what do you tend to do?

- *Do you involve your spouse/partner in decisions about your health?.*
- *Do you speak to other people?*
- *Do you self-medicate?*
- *What other things do you do when you are ill?*

When was the last time you went to the GP?

- *What was this for?*
- *What makes you decide to go to the GP?*

4 Beliefs about ill health

Would you consider yourself an optimist or a pessimist when it comes to your health?

- *If you are ill, are you relaxed or do you tend to assume the worst?*

Some people say that they feel older or younger than they are, how old do you feel?

Chest pain questions

5 History of the pain

When did you first have chest pain?

Could you describe the pain?

What has happened since this time, with regard to the chest pain?

6 Perceived cause of the pain

What did you think was the cause of the chest pain?

Why did you think that this might be the cause?

Do you feel you know what the symptoms of heart diseases are?

7 Feelings about the pain

How did the pain make you feel?

Why did it make you feel this way?

8 Actions in relation to the pain

What did you do about the pain?

Why did you take this course of action?

Has the chest pain made you think or feel differently about your life or your health?

Have you made any changes in your life as a result of the pain?

9 Risk of heart disease?

Did you have an idea of the type of person who is likely to get heart disease?

Did you consider yourself to be at risk of heart disease?

Why is this? (explore risk factors and family history)

Do you think that heart disease is something which mainly affects men or women or both equally?

Appendix 5

Coding schedule

Perceptions of chest pain: coding schedule

- (2) /CHEST PAIN**
- (2 1) /chest pain/cp account**
- (2 1 1) /chest pain/cp account/clarity of account
- (2 1 2) /chest pain/cp account/assoc symptoms
- (2 1 3) /chest pain/cp account/jokes
- (2 2) /chest pain/cp emotion**
- (2 3) /chest pain/cp action**
- (2 3 1) /chest pain/cp action/lay consultation
- (2 3 2) /chest pain/cp action/medical consultation
- (2 3 2 1) /chest pain/cp action/medical consultation/reasons
- (2 3 2 2) /chest pain/cp action/medical consultation/reasons for delay
- (2 3 2 3) /chest pain/cp action/medical consultation/urgency
- (2 3 3) /chest pain/cp action/self care
- (2 4) /chest pain/cp knowledge**
- (2 5) /chest pain/cp consequence**
- (2 5 1) /chest pain/cp consequence/restriction of activities
- (2 5 2) /chest pain/cp consequence/adaptation
- (2 6) /chest pain/cp cause**
- (2 6 1) /chest pain/cp cause/lists of causes
- (2 6 2) /chest pain/cp cause/reasons for beliefs
- (2 6 3) /chest pain/cp cause/self blame
- (2 7) /chest pain/cp Drs reactions**
- (2 7 1) /chest pain/cp Drs reactions/attitudes
- (2 7 2) /chest pain/cp Drs reactions/actions
- (2 8) /chest pain/CHD others**
- (2 9) /chest pain/cp other's reactions
- (2 10) /chest pain/CHD risk**
- (2 10 1) /chest pain/CHD risk/perceived risk
- (2 10 1 1) /chest pain/CHD risk/perceived risk/reasons
- (2 10 2) /chest pain/CHD risk/stereotype
- (2 10 3) /chest pain/CHD risk/gender
- (2 11) /chest pain/cp investigations**
- (2 12) /heart/other**
- (2 13) /chest pain treatment**

- (3) /ILLNESS**
- (3 1) /illness/illnesses**
- (3 1 1) /illness/illnesses/definitions
- (3 1 2) /illness/illnesses/multiple morbidity
- (3 1 3) /illness/illnesses/chain of illness
- (3 1 4) /illness/illnesses/contradictions
- (3 1 5) /illness/illnesses/relative health
- (3 2) /illness/illness attitude**
- (3 3) /illness/illness action**
- (3 3 1) /illness/illness action/lay consultation
- (3 3 2) /illness/illness action/medical consultation
- (3 3 2 1) /illness/illness action/medical consultation/reasons
- (3 3 2 2) /illness/illness action/medical consultation/reasons for delay
- (3 3 2 3) /illness/illness action/medical consultation/gender
- (3 3 3) /illness/illness action/self care
- (3 3 3 1) /illness/illness action/self care/alternative
- (3 4) /illness/illness consequences**
- (3 5) /illness/illness causes**
- (3 5 1) /illness/illness causes/self blame

- (3 6) /illness/age
- (3 7) /illness/death
- (3 8) /illness/illness knowledge
- (3 9) /illness/lay comments
- (3 10) /illness/illness others
- (3 11) /illness/treatment
- (3 11 1) /illness/treatment/hormones
- (3 12) /illness/investigation

(4) /HABITS

- (4 1) /habits/diet
- (4 2) /habits/smoking
- (4 3) /habits/alcohol
- (4 4) /habits/exercise
- (4 4 1) /habits/exercise/type of exercise
- (4 4 2) /habits/exercise/reasons
- (4 5) /habits/illness prevention

(5) /MEDICAL PROFESSION

- (5 1) /medical profession/illness medical reaction
- (5 2) /medical profession/views of health care
- (5 3) /medical profession/medical prof relationships
- (5 3 1) /medical profession/medical prof relationships/priveleged relationships
- (5 3 2) /medical profession/medical prof relationships/communication

(6) /FAMILY

- (6 1) /family/family structure
- (6 2) /family/FH CHD
- (6 3) /family/family illness
- (6 4) /family/family relationships

(7) /SOCIAL

- (7 1) /social/social class
- (7 2) /social/gender
- (7 3) /social/employment
- (7 4) /social/housing
- (7 5) /social/stress
- (7 6) /social/religion
- (7 7) /social/money
- (7 8) /social/life circumstances
- (7 9) /social/future
- (7 10) /social/opt or pess
- (7 11) /social/support
- (7 12) /social/sex
- (7 13) /social/activities

(8) /RESEARCH

- (8 1) /research/recall
- (8 2) /research/illness metaphors
- (8 3) /research/Dr as researcher
- (8 4) /research/language
- (8 5) /research/research other
- (8 6) /research/confidentiality
- (8.7) research/humour

(9) /BODY

- (9 1) /body/views of body
- (9 2) /body/control

Appendix 6

Published paper on reflexivity

The 'doctor' or the 'girl from the University'? Considering the influence of professional roles on qualitative interviewing

Helen Richards and Carol Emslie

Richards H and Emslie C. The 'doctor' or the 'girl from the University'? Considering the influence of professional roles on qualitative interviewing. *Family Practice* 2000; **17**: 71–75.

Background. Qualitative research methods are now recognized as valuable tools for primary care. With the increasing emphasis on evidence-based medicine and critical appraisal of published work, it is important that qualitative researchers are transparent about their methods and discuss the impact of the research process on their data.

Objectives. To consider the impact of the professional background of researchers on in-depth interviewing in primary care.

Methods. We compare interactions between the interviewer and respondents in two qualitative interview studies of heart disease. Both samples consisted of 60 middle-aged men and women from a range of social backgrounds living in the West of Scotland. One study was conducted by a GP and the other by a sociologist.

Results. Some interview interactions were common to both researchers; for example, interviews were often regarded by respondents as therapeutic. However, some interactions seemed to be related to the researcher's professional background. The GP's perceived higher status led to obscuring of her personal characteristics. The sociologist was often perceived as a 'young woman' rather than defined by her professional role. Thus respondents' perceptions of the interviewer influenced the interview interactions.

Conclusions. Appraising qualitative research depends on the transparency with which the research process is described. Awareness of professional background is particularly important for university departments of primary care (which often include doctors, nurses and social scientists) and should be considered carefully in designing, carrying out and disseminating the results of qualitative studies.

Keywords. Heart disease, methodology, qualitative research, reflexivity.

"The scientific observer is part and parcel of the setting, context and culture he or she is trying to understand and represent."¹ (p. 486).

Introduction

Qualitative methods make a valuable contribution to primary care research.^{2–4} However, assessing the standard of qualitative research depends on the transparency with which the research process, and its impact on the

data, are described.^{5–8} One part of this process which is rarely considered in primary care research is the interaction between the interviewer and respondent. In this paper, we consider the impact of the professional background of the researcher on this interaction. This is particularly relevant for university departments of general practice which tend to include researchers from such diverse professional backgrounds as general practice, nursing and sociology, who may be working as part of a team.⁹

Social scientists have considered how contextual details, such as the interview setting and the interaction between their own and the respondent's personal characteristics, may influence their data. Awareness of these factors is sometimes called reflexivity. Researchers have been encouraged to reflect upon their own gender, ethnic and class identities and "to abandon the illusion that

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researchers, their informants, and the research setting do not influence each other reciprocally"¹⁰ (p. 882). Similarly, feminist writers have stressed that researchers' own experiences and interests influence their research¹¹⁻¹³ from the choice of research topics to the way in which it is disseminated. However, 'technical' aspects of the interview (e.g. the number conducted, their length and content, how they were recorded) are still much more likely to be included in the literature than information about the nature of interactions between the interviewer and respondents.^{14,15}

The absence of contextual detail in qualitative research published in general practice has been highlighted recently.¹⁶ This may be due largely to the restrictions that medical journals place on the length of articles: few allow more than 2500 words. The result is that information about the professional background of researchers, the relationship between the interviewer and respondents and the context in which interviews take place is rarely provided, making it difficult both to evaluate studies and for new qualitative researchers to gain guidance from published accounts. Hoddinott, a GP researcher, has discussed the influence of professional background on the qualitative interview. In a study on attitudes to breast feeding,^{17,18} she carried out some interviews stating she was a GP, and others saying she was a 'researcher'. She found that her interviewing skills were better when she declared that she was a GP, and concludes that in future she would make her professional background clear to all respondents.

Here, we wish to extend Hoddinott's account of the influence of professional background on interviewing by comparing our experiences as two researchers from different professional backgrounds (general practice/sociology), working on similar qualitative studies in the same university department of general practice. First, we provide some background about the studies and about ourselves. Then, we reflect upon types of interview interactions common to both researchers. Finally, we provide some examples of the ways in which professional background and personal characteristics may influence interview interactions.

Background

The studies

Both studies involved in-depth interviews in the West of Scotland with 60 middle-aged men and women of varied occupational social class, classified as 'middle-class' if they were engaged in non-manual work (I, II or IINM) and 'working-class' if engaged in manual work (IIIM, IV or V). The family history study,¹⁹ carried out by C Emslie, explored respondents' perceptions of whether they had a family history of heart problems, and the chest pain study, carried out by H Richards, explored perceptions of chest pain. Both qualitative samples were drawn from

previous large population studies^{20,21} which involved structured questionnaires and clinical measurements (electrocardiographs and blood tests). Respondents in the chest pain study were slightly older (between 45 and 64 years, compared with between 41 and 51 years in the family history study) and, because experience of chest pain was a selection criterion, they were more likely to have had significant medical problems. Respondents in both studies were sent a letter, on the university department of general practice letterhead, explaining the purpose of the study, followed by a telephone call to arrange the interview at a place convenient to them. Interviews were tape-recorded and transcribed in full. Extensive field notes (including observations about the respondent and their setting, initial ideas about emerging themes for analysis, methodological issues and personal notes) were recorded after each interview.

The researchers

C Emslie is a sociologist and H Richards is a GP. Both are white, female and middle-class, and have similar experience of qualitative research. C Emslie is Scottish and in her late twenties, H Richards is English and in her mid-thirties.

Reflections on interview interactions

While certain interactions were noted by both researchers, some seemed to be associated with being a doctor or a sociologist. We discuss these in turn. Respondents' words are presented in italics and labelled with their gender, social class and ID number, and the interviewer's initials where necessary.

Interactions common to both researchers

The similarity between research interviews and therapeutic interactions has been widely discussed.²²⁻²⁵ Qualitative interviews are often described as 'non-directive', a term which originates from psychotherapy, where patients are encouraged to express problems in their own terms "stimulated by an interested and sympathetic listener"²⁶ (p. 111).

Some respondents in both studies stated that they found interviews therapeutic. For example, when asked to describe her health problems, one respondent replied: "*Oh, I love this. I love it. I think that once you get to a certain age, your doctors are not interested in you*" (female, working-class, R31, HR). Another respondent commented that an interview had been "*cathartic*", like "*sitting in the psychiatrist's chair*" (male, middle-class, R56, CE).

Respondents also disclosed sensitive and confidential information. One respondent who still had chest pain despite a recent coronary bypass operation said "*I don't mention it to anyone, if I mentioned it to S (wife), she'd just get excited about it*" (male, middle-class, R1, HR). In

the family history study, men and women talked about their difficult childhoods, and alcoholism, illegitimacy and suicide amongst family members. A number of respondents became upset when talking about painful or early deaths of family members (CE/HR) and about experiences of caring for elderly relatives (HR). For example, one woman became tearful when talking about her elderly mother: "It ended up anyway, she was the one sitting on my knee" (female, working-class, R32, HR). Considering respondents' emotions in primary care research is important because respondents often talk about sensitive subjects such as personal relationships and health, and yet, with few exceptions,^{14,22,27} this issue is not addressed in the literature.

Interactions specific to each researcher

The GP researcher. I decided, for methodological and ethical reasons, to be explicit about my professional background, and introduced myself as a GP involved in research. I made it clear that I was not practising currently. I gave no medical advice; general queries were dealt with at the end of the interview and respondents were referred to their own GP as appropriate.

Many of the working-class respondents were deferential: the title 'Doctor' was often used and I was introduced by several interviewees to family members as 'the doctor'. One respondent apologized for taking up my time, even though the interview took place at my request, and one revealed his view of doctors by saying of his own GP: "He's the same sort of man as a priest type thing . . . they're not far away from the same profession" (male, working-class, R46). Another respondent referred to his GP as "a saint" (male, working class, R56).

Deference was not observed among the middle-class respondents who, in contrast, tended to align themselves with me by assuming commonality of opinions and experience. In particular, there were references to friendships and insider knowledge which had led to special medical treatment. For example, one respondent who was in a profession allied to medicine said: "There's a waiting list for bypasses obviously but, in a sense, . . . I'm on an inside track" (male, middle-class, R18). Another middle-class man reported how he was able to avoid the GP appointment system by knocking on the surgery door when his GP was working late, and there were several examples of friendships between respondents and their GPs and consultants. The assumed commonality of experience was stronger in male than female respondents.

Respondents from all social backgrounds asked clinical questions. For example, with regard to cholesterol, one respondent said: "You might be able to tell me something about that. Somebody was telling me that they've reduced the upper limit from . . . six down to four point six" (male, middle-class, R29). In relation to heart disease and the menopause, a woman asked: "Once that [periods] stops like, you're at higher risk . . . Is this true?"

(female, working-class, R31). Respondents frequently gave detailed accounts of hospital appointments and medical treatments. Another example of the interview taking on elements of the consultation was when respondents talked about sexual health problems. One response to the question "Have you had any other sort of health problems?" was: "Ehh, the sexual one are you talking about?" (male, working-class, R49), and a woman, talking about her hysterectomy, said: "Even sexually it's changed me, I can't be bothered to be touched, I just don't have the same urges any more" (female, middle-class, R2).

When asked at the end of the interview whether there was anything they would like to add or ask, respondents expanded on their health problems, asked health-related questions and gave their opinions of doctors and other aspects of the health service. One woman said: "Excuse me saying it, I don't think [doctors] realise how frightened people are when having this sort of thing [operations]" (female, working-class, R13). In this case, the respondent apologized for expressing a negative view of doctors.

The sociologist. I chose to introduce myself to respondents as a 'researcher' rather than as a 'sociologist' because the role of a researcher is more commonly recognized and is easier to explain. I felt, for a number of reasons, it was vital to distance myself from medical professionals. First, the primary focus of the study was on lay perceptions of family history of heart disease; secondly, respondents had already provided clinical measurements for the earlier epidemiological study; and thirdly, respondents knew that the study was based in a university department of general practice. To reinforce this, I did not use my title ('Doctor') on the introductory letter, stressed at the beginning of the interview that I was not medically qualified, and asked respondents to explain even common medical conditions to me. This was important both ethically and practically, as I did not wish respondents to focus narrowly on medical issues.

I arrived on respondents' doorsteps, a young, fairly casually dressed woman without medical qualifications or the usual signs of professional status (suit and car). On the other hand, I was associated with a well-known health study at the university and produced my 'tools of the trade' (a tape recorder and topic guide). These seemingly contradictory signs of status seemed to make me rather hard to place, particularly for some male respondents. It has been noted that gender is often highlighted when women interview men because the qualitative researcher "is required to take on an acquiescent, attentive, and assenting role very close to traditional notions of femininity"¹⁵ (p. 630). A number of (mainly male) respondents attempted to resolve some of these contradictions in status by asking me at the end of the interview if I was a student, assuming that the research was for a thesis. On another occasion, a respondent (female, working-class, R33) introduced me as "the girl from the

University” to each member of her family as they arrived home from work. When her husband arrived, he voiced his concerns to both of us that market researchers would contact them as a result of the interview. The respondent was clearly embarrassed and assured her husband that I was a university researcher and would not pass on their details to anyone else.

In contrast, my professional status was much more apparent when respondents chose to be interviewed at the university. Similarly, a few middle-class women emphasized my professional status by asking me about my career. One woman was very eager to introduce me to her family after the interview (female, middle-class, R4). She informed her husband that I had a PhD, and introduced me as a potential role-model to her teenage daughter, who was interested in medicine as a career. These examples illustrate how contextual details of the interview, such as the gender and age of the interviewer and respondent and where the interview takes place, interact and influence the interview process.

Differences in social class were referred to obliquely. Respondents asked me where I lived, or where I had been brought up. One respondent referred to her “*broad Scottish voice*” on the tape (female, working-class, R44). While most respondents expected me to understand colloquial Scottish phrases and expression, others checked that I followed what they were saying.

Although I did not ask respondents anything about their doctors or their views of medical professionals, they often commented on them. These comments were usually unfavourable, perhaps because I had stressed that I was not medically qualified. For example “*I wish doctors would listen to you more, because you’re not medically minded, so when you tell them something they have this preconceived idea of what is wrong with you, and they’re not listening to what you’re actually trying to tell them*” (female, middle-class, R15). One man said that were it not for the hospital health checks his workplace provided, “*I’d be relying on my GP for my health-check, and you really don’t want to know what I think about GPs!*” (male, middle-class, R17).

At the end of the interview, respondents were asked what they had thought of the interview and if they had any questions. A number of respondents referred back to the clinical measurements taken as part of the general population survey. I reassured respondents that any abnormal results would have been passed on to their GP and stressed that I did not have access to these results. Most respondents had no previous experience of an in-depth interview and many said they had not been sure what to expect. This was illustrated by the comment of a busy teacher who asked me during the initial telephone call if I could just “*send her a questionnaire instead*” (female, middle-class, R54). Respondents from all backgrounds wanted to know what would happen to the interview material and were interested to know more about the research process. Finally, when interviews

were conducted in respondents’ homes in the evening, they showed concern about me getting home by public transport.

Discussion and conclusions

In this paper, we compared the interview process in two qualitative studies of heart disease. Both authors found that interviews were described by some respondents as therapeutic. Qualitative interviews are likely to be perceived as therapeutic by respondents regardless of the professional background of the interviewer. However, the authors found some notable differences in interview interactions. Doctors have a more clearly defined role and higher social status than sociologists. This difference in status led to the more frequent observation by HR than CE of deference amongst working-class respondents and social alignment amongst middle-class respondents.

While we have concentrated on the impact of professional background on interviewing, personal characteristics (such as gender, age, ethnicity and social class) of the researcher and the respondent are equally important. These characteristics are not discrete and unchanging, but dynamic and interdependent, constantly constructed during the interview. Morgan²⁸ argues that “gender (in common with other personal characteristics) is a latent variable, exaggerated in some cases and relatively muted in others” (p. 46). We found that this was also true of professional background. The professional identity of ‘the doctor’ is so well known that it became an exaggerated variable in HR’s interviews, overshadowing her personal characteristics. In contrast, professional background was much more muted for CE, so gender and age were key variables in identifying her as ‘the girl from the University’.

Respondents’ preconceptions of the roles of doctors and university researchers also influenced the content of the interviews, particularly the topics mentioned spontaneously by respondents. For example, respondents asked HR health-related questions (including those relating to sexual health), whereas they tended to talk to CE about broader, non-health-related topics.

We are not suggesting that social scientists collect ‘better’ data than GPs, or vice versa, but that it is important that researchers reflect upon their professional backgrounds and personal characteristics and consider how these influence the way in which they gather and analyse data. Respondents have definite preconceptions about the role of a GP; in contrast, a sociological ‘researcher’ is an unknown quantity and respondents took more time to place the interviewer. GP researchers must first decide whether or not to declare their professional background. If they do make it clear that they are medically qualified, they should be aware of respondents’ possible preconceptions and take care to explain their current role as

researcher. Sociologists and other social scientists, who have a less clearly defined professional role and status, face the similar challenge of making their professional background and interests clear.

The main limitation of this paper is that the two studies had different recruitment criteria. Participants in the chest pain study were more likely to have had significant medical problems and undergone investigations and treatment than those in the family history study. However, the similarity of the studies in terms of sample composition, interview topic and geographical area provided an unusual opportunity to examine the influence of professional roles on the interview process.

One of the strengths of university departments of general practice is their eclectic composition: anthropologists, psychologists, nurses, sociologists and GPs all bring different perspectives to research. Because of this diversity, the impact of professional background should be considered carefully when designing, carrying out and disseminating qualitative research. It has been argued that "who you are affects what you get told"²⁹ (p. 114); we suggest that who respondents *think* you are affects what you get told. In this study, we have focused solely on data collection. Future work is planned to explore the influence of professional roles on other stages of the research process.

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