

Cardiac Rehabilitation patients' perspectives on Coronary Heart Disease and treatment: a qualitative study

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Abstract

UK hospital-based Cardiac Rehabilitation (CR) programmes offer eligible Coronary Heart Disease (CHD) patients information on various issues including lifestyle modification and medicines. However, CR patients' perspectives on medicine-taking and lifestyle modification in relation to their perspectives on their risk of experiencing further CHD-related events remains under-researched. This study explored these topics.

Following ethical approval, a qualitative approach was taken that drew on the broad principles of grounded theory. In-depth, audiotaped interviews were conducted with sixteen CR patients approximately three months after hospital discharge. Second interviews explored whether heart attack CR patients' perspectives on risk, medicines and lifestyle modification had changed when interviewed again approximately nine months later. The perspectives of a group of CR patients' who had not had a heart attack were explored for comparison.

Findings suggested that CR patients made sophisticated yet uncertain assessments of their risk. This did not just involve identifying lifestyle factors needing change or attributing the likelihood of experiencing further CHD-related events to chance or heredity alone; patients tended to also consider information about heart damage or current heart function. Heart attack patients commonly feared recurrence, which appeared to heighten short-term perceptions of risk but longer-term perspectives on risk appeared similar to CR patients who had not had a heart attack.

CR patients tended to only maintain changes to aspects of lifestyle perceived as causes, rather than viewing lifestyle recommendations as standards to achieve. Some heart attack patients initially changed aspects of lifestyle they did not cite as a cause, which seemed to be associated with heightened risk perceptions, since these changes tended not to be maintained. CR patients reported continuing to take heart-related medicines and viewed them as important to reduce their risk, despite disquiet about medicines causing harm being common. These findings have implications for health professionals' practice and CR programme improvement.

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Chapter One

Introduction

1.1 Forward

This thesis presents a qualitative study of cardiac rehabilitation (CR) patients' perspectives on Coronary Heart Disease (CHD) and its treatment (i.e. medicines and lifestyle modification). An overview of CHD and a description of the CR programme undertaken by the patients in this study are provided in section 1.2. After this, the study is briefly introduced and the organisation of the thesis is outlined in section 1.3.

1.2 Overview of CHD and cardiac rehabilitation

From a biomedical perspective CHD can perhaps be best viewed as a continuum of a pathological process, in which the coronary arteries gradually thicken, harden and atherosclerotic plaques develop that further occlude blood flow. This leads to clinical manifestations such as angina and acute coronary events resulting from disruption of plaques, such as acute coronary syndromes, myocardial infarction and death. In this thesis the term "heart attack" is used rather than "myocardial infarction" because this is the term that the patients used.

CHD is a leading cause of morbidity and mortality, particularly in the Western World. In the UK it is estimated that 147 000 men and 121 000 women have a heart attack each year (NICE 2007). There is also wide variation in UK CHD death rates according to age, gender, socio-economic status, ethnicity and geographical location. The CHD death rate is three times higher in men aged less than seventy-five years than in women and

twice as high in socio-economically disadvantaged areas as compared to more affluent areas (Department of Health 2003). The CHD death rate among people of South Asian origin is nearly fifty-percent higher than the general population (NICE 2007).

The White Paper *Saving Lives: Our Healthier Nation* (Department of Health 1999) outlined Government health policy aimed at reducing significant causes of mortality and morbidity in the population, such as CHD. Evidence-based national standards for the prevention, diagnosis and treatment of CHD were established in the National Service Framework (NSF) for CHD (Department of Health 2000), which set out a ten-year programme to reduce inequalities and improve health and quality of care. This has been supported by subsequent White Papers, such as *Building on the Best: Choice, Responsiveness and Equity in the NHS* (Department of Health 2003) and *Choosing Health: Making healthy choices easier* (Department of Health 2004).

The NSF for CHD included strategies to reduce risk factors in the whole population, strategies aimed at people at high risk of developing manifestations of CHD and secondary prevention strategies aimed at people who already exhibited such manifestations. Assessment of cardiovascular risk is a key feature in this and focuses on modification of risk factors such as smoking, high cholesterol, hypertension, obesity and physical inactivity (Joint British Societies 2005). This was incorporated into the General Medical Services contract, in which practices are required to keep a register of patients with CHD and ensure that they receive appropriate treatment and advice on prevention (British Medical Association 2004). These strategies are supported by recent national clinical guidelines that set out evidence-based recommendations on lifestyle and drug therapy (e.g. Joint British Societies 2005, NICE 2007).

Lifestyle recommendations concern stopping smoking (where relevant), diet, physical exercise and weight (Department of Health 2000, Joint British Societies 2005, NICE 2007). A Mediterranean-style diet is recommended, which includes at least five portions of fresh fruit and vegetables a day, at least two servings of oily fish per week and minimising saturated fat intake by replacement with monounsaturated fats (Joint British Societies 2005, NICE 2007). Other dietary recommendations include limiting salt intake to less than six grammes daily and alcohol intake to less than twenty-one units per week for men and fourteen units per week for women (Joint British Societies 2005, NICE 2007). Regular physical exercise is recommended for at least twenty to thirty minutes per day on most days of the week (Joint British Societies 2005, NICE 2007). It is recommended that ideal body weight (i.e. body mass index twenty to twenty-five kilograms per square metre) be achieved and maintained (Joint British Societies 2005).

The guidance recommends the use of aspirin, beta-blockers, ACE inhibitors and cholesterol-lowering drugs (e.g. statins) for secondary prevention of CHD, especially following a heart attack (Joint British Societies 2005, NICE 2007). For example, recent National Institute for Health and Clinical Excellence guidelines for the secondary prevention of heart attacks (NICE 2007) recommends that, unless contra-indicated, all patients should be prescribed antiplatelet therapy with aspirin (and clopidogrel for a limited duration in most cases), a beta-blocker, an ACE inhibitor and a statin. Drugs such as angiotensin receptor blockers, calcium channel blockers and alpha-blockers may be prescribed as an adjunct or alternative to beta-blockers or ACE inhibitors (usually to control blood pressure). Drugs such as nitrates, calcium channel blockers and nicorandil may be prescribed to prevent angina. Other lipid lowering drugs, such as gemfibrozil, may be prescribed as an alternative to statins. Diuretics (e.g. frusemide)

may be required to reduce breathlessness or peripheral oedema and anticoagulant therapy with warfarin may be prescribed in certain circumstances instead of aspirin. Patients are usually prescribed a glyceryl trinitrate (GTN) spray for relief of angina.

Cardiac rehabilitation (CR) is a secondary prevention strategy that was defined by the World Health Organisation in 1993 as:

“...the sum of activities required to influence favourably the underlying cause of the disease as well as the best possible, physical, mental and social conditions, so that they (people) may, by their own efforts preserve or resume when lost, as normal a place as possible in the community. Rehabilitation cannot be regarded as an isolated form or stage of therapy but must be integrated within secondary prevention services of which it forms only one facet.” (World Health Organisation 1993)

CR has been shown to benefit patients following a heart attack, as well as before and after coronary artery bypass graft (CABG) surgery (Department of health 2000, Williams *et al* 2006). Benefits have also been shown in patients with stable angina and heart failure (Department of health 2000, Williams *et al* 2006). Traditionally, CR programmes were hospital-initiated and only provided for heart attack patients but improved and increasingly available cardiac surgical interventions, particularly percutaneous techniques, have resulted in increasing numbers of patients who can benefit from CR (Williams *et al* 2006). However, a significant proportion of eligible patients fail to receive CR, such as patients ineligible for thrombolysis, socially deprived patients, women, ethnic minorities and the elderly (Department of Health 2000, Williams *et al* 2006,

Bethell *et al* 2006). In response, the NSF for CHD set a target for eighty-five percent of eligible patients to be offered CR. However, there has been no subsequent increase in the enrolment of eligible patients into CR in the UK (Bethell *et al* 2006). Indeed, it has been found that only twenty-six percent of eligible heart attack patients and only eighteen percent of eligible patients who had undergone percutaneous techniques were included in CR compared to seventy-two percent of eligible CABG patients (Bethell *et al* 2006). Improving the quantity and quality of CR provision has since become a priority in the further implementation of the NSF for CHD (Department of Health 2007).

To reduce variation in service provision, the NSF for CHD specified interventions that should be offered to all patients eligible for CR, unless contra-indicated (Department of Health 2000). Typically this involves multidisciplinary input from health professionals such as nurses, physiotherapists, occupational therapists, dietitians, pharmacists and social workers. This input includes assessment of individual physical, psychological and social needs. It also involves provision of structured exercise sessions and information on various issues including lifestyle recommendations and the use, benefit and harms of medicines (Department of Health 2000). The CR programme that the patients in this study attended ran for six weeks on a one session per week basis. Each session included group-based information provision, supervised exercises and relaxation. Health professionals spoke to patients (for approximately forty-five minutes per session) on various topics including diet, exercise, medicines, stress management and local CHD patient groups. Patients were also given written information about these topics, for example the British Heart Foundation's booklets.

1.3 Introduction to the study and organisation of the thesis

This study originated from a research interest in CR patients' perspectives on the use of medicines in relation to their perspectives on lifestyle modification and CHD (as discussed in section 3.3.1). Gaps in the existing research on lay perspectives on CHD (discussed in chapter two) supported a need for this. A qualitative approach to the study was taken that drew on the broad principles of grounded theory. The rationale for this, methodological considerations, the specific aims of the study and the methods used are discussed in chapter three. The initial stage of the study involved a series of in-depth interviews with a sample of CR patients approximately three months after discharge from hospital. The analysis of the findings from the interviews with the CR patients who had had a heart attack is discussed in chapters four and five. These findings established a focus on how patients' perspectives on their risk of experiencing further CHD-related events related to their perspectives on taking medicines and lifestyle modification. A second series of interviews with the patients was conducted approximately a year after discharge from hospital to explore whether their perspectives on risk, medicines and lifestyle modification had changed over time. The analysis of the findings of this second stage of the study is discussed in chapter six. The third stage of the study concerned CR patients who had not had a heart attack and their perspectives on risk, medicines and lifestyle modification. This stage was undertaken for comparison with the heart attack CR patients' perspectives, as discussed in section 3.3.1. The analysis of the findings from this stage of the study is discussed in chapter seven. In chapter eight the significance of the findings is discussed and how these relate to the literature. The implications of the study and reflexive issues are also discussed.

Chapter Two

Lay perspectives on CHD: a review of the literature

2.1 Introduction

In this chapter a review of the literature on lay perspectives on CHD is presented, which begins with a discussion of the approach taken toward searching and reviewing the literature. The findings are broadly divided into three main topics: lay perspectives on the risk of CHD; patients' perspectives on having CHD; and patients' perspectives on health service provision for CHD. The topic on patients' perspectives on having CHD is divided into three subsections: responses to manifestations of CHD; perceptions and experiences of CHD; and perspectives on treatment of CHD. Gaps in the literature that are relevant to this study are highlighted in the summary at the end of the chapter.

2.2 Literature review methods

2.2.1 Literature search strategy

A literature search was performed in March 2003, and repeated at regular intervals (most recently February 2008) to identify literature on lay perspectives on CHD. The search strategy involved using Boolean operators for combinations of the following keywords: "coronary heart disease", "coronary artery disease", "ischaemic heart disease", "heart disease", "myocardial infarction", "heart attack", "lay perception", "patient perspective", "qualitative research", and "ethnography". Equivalent terms in

thesauruses or Mesh browsers were used wherever possible. Searches were limited to English language articles only but no other limits were imposed.

The databases that were searched included: Allied and Complementary Medicine (AMED) from 1985, Applied Social Sciences Index and Abstracts (ASSIA) from 1997, British Nursing Index from 1985, Cumulative Index to Nursing and Allied Health Literature (CIANHL) from 1982, Embase from 1980, International Bibliography of the Social Sciences (IBSS) from 1951, International Pharmaceutical Abstracts from 1970, Medline from 1966, PsycINFO from 1872, Sociological Abstracts from 1963, and Web of Science from 1945. In addition, a Zetoc eMail alert was established in March 2003 to identify new papers using the key word "qualitative". These searches were supplemented by a hand-search of reference lists in articles identified.

By its very nature the literature on lay perspectives on CHD is predominantly, but not exclusively, qualitative since the less structured techniques used in qualitative studies (for example in-depth interviews) are better suited to exploring lay perspectives than quantitative studies, which typically ask people to select their preference from a limited range of pre-defined answers. However, effective searching for qualitative literature is notoriously difficult (Barbour 2003a). One of the reasons for this is because of the huge number of journals that have published qualitative research, some of which are not included in the main electronic databases (Barbour 2003a). In addition, electronic databases use a limited range of keywords that varies between databases, and usually only describes general topic areas rather than researchers' specific interests (Barbour 2003a). Subsequently, it is possible that some relevant papers were overlooked despite a thorough search being made.

2.2.2 Inclusion criteria

The inclusion criteria were intended to be broad. Any English language articles were included that were predominantly concerned with lay perspectives on CHD, which included research reports, review articles of research studies and articles that commented on research studies. However, abstracts from conferences or research theses, where a full paper had not been published, were not included on the grounds of being too brief for meaningful assessment. Articles were included if they concerned patients with a manifestation of CHD, or people at risk of CHD, or concerned health service provision for patients with CHD/ at risk of CHD. However, despite CHD being a leading cause of heart failure, there are a variety of other causes, and therefore articles were not included that concerned patients with heart failure or concerned health service provision for heart failure.

A variety of terms with different, overlapping or interchangeable meanings including “cardiac”, “cardiothoracic” and “cardiovascular” are used in the literature to categorise patients. Since these terms do not exclusively refer to CHD patients or people at risk of CHD, papers using these terms were excluded unless it was also specified that all of the patients had, for example, had a heart attack, which indicated that all of the patients had CHD. In order to determine whether articles met these criteria, the lists of titles and abstracts were examined from the searches and the whole paper was examined where doubt remained. As a result a total of 173 papers were included by the time of writing. These papers are discussed under three main headings: perspectives on the risk of CHD (section 2.3); perspectives on having CHD (section 2.4); and, perspectives on health service provision for CHD (section 2.5).

2.3 Perspectives on the risk of CHD

Twenty-seven papers resulting from nineteen studies specifically explored lay perspectives on the risk of CHD. A key concept that emerged from this literature is the concept of coronary candidacy or the “kind of person who gets heart trouble” as proposed by Davison and colleagues (1991). Based on extensive fieldwork, that involved participant observation and in-depth interviews in South Wales in the late 1980s, they argued that people had a coherent approach to assessing the risk of CHD and the likelihood of that actually happening (Davison 1989, Davison *et al* 1989, 1991, 1992, Frankel *et al* 1991).

They noted that their study population had a significant knowledge of the modifiable risk factors for CHD, not least as a result of a recent high profile coronary prevention campaign. This knowledge had been incorporated into pre-existing ideas about how, why and when CHD might occur, which happened through a process they termed “lay epidemiology”, where theories concerning the preventability or inevitability of ill health are developed and then refined over time. They argued that “official” messages about CHD are incorporated within lay knowledge to form a framework, which they termed “coronary candidacy”. This may be used to assess the risks of CHD in everyday life and explain why some people are susceptible to CHD whilst others are not.

The coronary candidacy framework may identify individuals at risk of CHD in three ways: appearance (e.g., overweight, unfit, red-faced individuals may be considered to be candidates); social context (e.g., people with a family history of CHD and people in stressful or sedentary jobs may be considered to be candidates); and personal

information (e.g., people who smoke, eat a high fat diet, drink a lot of alcohol or who are “worriers” may be considered to be candidates)(Davison *et al* 1991).

Built in to this framework is the recognition that candidacy only increases the risk and is not guaranteed to result in CHD; some individuals who are not identified as candidates suffer CHD whilst some obvious candidates do not. These two types of person were termed the “Uncle Norman” figure who enjoys considerable longevity despite smoking and drinking heavily amongst other risky behaviours, and “The last person you’d expect to have to have a coronary”, who despite being health-conscious and avoiding such risky behaviour still succumbs to CHD. This is explained as a matter of chance, also known as luck, fate or destiny. Davison and colleagues (1991) propose that the observation that “it never seems to happen to the people you’d expect it to happen to” becomes an integral component of the coronary candidacy framework and argue that:

“Lay epidemiology readily accommodates official messages concerning behavioural risks within the important cultural fields of luck, fate and destiny. This simultaneously constitutes a rational way of incorporating potentially troublesome information, and a potential barrier to the aims of health education.” (Davison *et al* 1991)

Emslie and colleagues (2001a) suggested that “the kind of person who gets heart trouble” may be better described as “the kind of person who has a heart attack” since their study respondents focused almost entirely on heart attack rather than other manifestations of CHD. It was pointed out that death from a heart attack may be seen as a “good way to go”, since this is presumed to be quick rather than a slow painful

death from cancer, for example and that this may undermine motivation to modify lifestyle risk factors (Emslie *et al* 2001b). They also argued that age has a significant bearing on coronary candidacy because in their study younger (than around retirement age) people suffering heart attacks tended to be seen as “The Last Person”, whilst coronary candidacy was often not applied to elderly people who died of CHD because “old age” tended to be perceived as the cause. In addition, they argued that the coronary candidacy framework is generally only applied to men and women are generally absent from this system. They noted that their respondents only talked about women with CHD when specifically asked and would typically refer to long-term CHD-related morbidity, rather than using the dramatic mortality-related language typically applied to men. A number of other studies, particularly those that only involved women, also found that CHD is often perceived as being a man’s disease. For example, Ruston and Clayton (2002) found that despite the presence of known risk factors their women participants did not tend to view themselves as being at risk of CHD unless they adopted a “man’s way of life”.

A number of other studies support Davison and colleagues’ (1991) finding that people tend to have a significant knowledge of the modifiable risk factors for CHD. These studies also demonstrate that knowledge of these risk factors does not necessarily lead to action to minimise them. Nic Gabhainn and colleagues (1999) found good knowledge levels of CHD risk factors across a range of socio-economic groups. They noted that men seemed less motivated to modify their lifestyle than women; older men tended to think it was too late and younger ones tended to think it was too soon. Narevic and Schoenberg (2002) studied lay explanations for high rates of CHD in Kentucky, and found that respondents in their quantitative telephone questionnaire study identified

most of the “biomedically acknowledged” risk factors. Meillier and colleagues (1996) found a considerable amount of background knowledge about the risks of CHD amongst the men they interviewed, but most did not follow generally accepted health advice. Bach Nielsen and colleagues (2005) found that lifestyle modification was limited, especially when it affected quality of life, in a group of people who knew they were at increased risk of CHD. Ritchie and colleagues (1994) found ample knowledge of risk factors and personal risk reduction among a group of manual workers, although this did not necessarily translate into action. They also found that health was often perceived to be influenced by luck or fate. Similarly, Angus and colleagues’ (2005) found that some of their participants talked about friends and relatives who had not seemed to be at risk of CHD but had still died from it.

Several studies looked at how other factors affect people’s perceived risk of CHD, such as family history of CHD, ethnicity, stress and hypercholesterolaemia. These study populations typically also had significant knowledge of modifiable risk factors for CHD, which was likewise incorporated within lay epidemiology regarding their own risk. Hunt and colleagues (2001) found that their participants’ perception of a family history of CHD depended on their gender, social class, knowledge of the health of their family members, and the number, age and closeness of their relatives with CHD. Even when participants did perceive that CHD did run in the family, or was a “family weakness”, they did not necessarily perceive themselves to be at risk. This was also found by Preston (1997) in her study of families who had a member with CHD. Farooqi and colleagues (2000) found a diverse range of attitudes and practices among “South Asians”, and highlighted the consequent danger of stereotyping. However, they found that whilst most participants were generally aware that a poor diet and lack of exercise

are risk factors for CHD, several participants did not seem to be aware that smoking is a risk factor. Stress was commonly perceived to be a risk factor for CHD, including stress related to immigrant status and racial disadvantage. Angus and colleagues (2007) also found that stress was commonly perceived to be a risk factor for CHD.

Senior and colleagues (2002) found in their study of people with hypercholesterolaemia that most people seemed to view themselves as being at increased risk of CHD, which was also found in other studies (Frich *et al* 2006, 2007, Hollman *et al* 2004). Troein and colleagues (1997) noted that many people found the diagnosis of hypercholesterolaemia hard to understand and accept, as they did not feel unwell. They noted that many participants were resistant to lifestyle changes and questioned the benefits of risk reduction. Tolmie and colleagues (2003) found patients were less likely to take statins if they did not feel ill. Durack Brown and colleagues (2003) found that people were often unsure what the cholesterol level meant and tended to view their risk of CHD as unpredictable or like “Russian roulette”. Lewis and colleagues (2003) noted that most of their study participants found difficulty in understanding the statistical basis for determining the benefits of such preventative treatment.

2.4 Perspectives on having CHD

2.4.1 Responses to symptoms of heart attack

Thirty-two papers arising from twenty-nine studies specifically explored people's responses to symptoms of heart attack. These studies indicate that the decision to seek medical care is a complex process that involves a variety of factors. Clark (2001), and Ruston and colleagues (1998) identified a number of stages involved in the decision-

making process. Clark (2001) focused on commonalities in decision-making, whilst Ruston and colleagues (1998) focused on characteristics associated with different delay times, since delay in seeking medical care is associated with significantly increased mortality and morbidity (Brink *et al* 2002, Clark 2001, Gassner *et al* 2002, Pattenden *et al* 2002, Richards *et al* 2002a, 2002b, Ruston *et al* 1998). Nevertheless, the stages proposed in these studies are essentially similar.

In the first stage the symptoms that the person experiences do not cause concern, they usually continue to go about their daily business and often try to ignore their symptoms. However, as the symptoms intensify (stage two) the person becomes increasingly aware that something is wrong. Commonly, people do not interpret their symptoms as being due to a heart attack, and often self-medicate (for example, with indigestion remedies), or try other self-care strategies to manage their symptoms (stage three). When these strategies fail to provide relief this prompts a period of re-evaluation and increasing crisis (stage four). At this point people often ask for advice from friends, family or work colleagues, which leads to the decision being made to seek medical help (stage five). Ruston and colleagues (1998) point out that the length of each stage is variable, and in some cases the decision to seek medical help is rapidly made, particularly if the person experiences classically sudden and severe symptoms such as chest pain.

Virtually all of the studies included in this section found that, initially at least, people often do not identify their symptoms as being due to a heart attack. Another common finding was that correct interpretation of symptoms is strongly influenced by perceived risk of CHD. The popular perception of a heart attack is of a dramatic event where

typically the victim suddenly collapses clutching their chest and often dies (Emslie 2001a). This may contribute to confusion in symptom identification and delay in seeking medical care, since for many people heart attacks are an evolving experience of symptom intensity (Arslanian-Engoren 2005, Brink *et al* 2002, Gassner *et al* 2002, Henriksson *et al* 2007, Johansson *et al* 2007, Kaur *et al* 2006, Pattenden *et al* 2002, Ruston *et al* 1998, Ruston & Clayton 2007, van Tiel *et al* 1998). Even knowledge of heart attack symptoms does not necessarily prevent delay in presentation, since symptoms may not be “typical” (Pattenden *et al* 2002, Ruston & Clayton 2007).

Studies commonly reported that people attempted to evaluate their symptoms and compared them to symptoms (for example, from indigestion) that they had already experienced. As common response is to self-medicate with indigestion remedies or analgesics, for example, or other self-care strategies such as lying or sitting down, walking around, taking a bath or drinking water (Johansson *et al* 2007, Schoenberg *et al* 2005). Some patients may try to “tough it out” to avoid seeking medical care for psychosocial reasons (for example fear of hospitals) or economic reasons (Schoenberg *et al* 2005). However, an important part of the decision-making process to seek medical care is that people commonly ask for advice from other people such as friends, family or work colleagues (Arslanian-Engoren 2005, Clark 2001, Henriksson *et al* 2007, Johansson *et al* 2007, Pattenden *et al* 2002, Ruston *et al* 1998).

A number of studies compared how women and men respond to symptoms of heart attack (Foster & Mallik 1998, Richards *et al* 2002a, van Tiel *et al* 1998, Zuzelo 2002). A common finding was that women are more likely than men to attribute their symptoms to a non-cardiac cause and to delay seeking medical care for longer, unless their

symptoms are severe (Albarran *et al* 2006, Arslanian-Engoren 2005, 2007, Dempsey *et al* 1995, Foster & Mallik 1998, Higginson 2008, Kaur *et al* 2006, Lisk & Grau 1999, McSweeney *et al* 2005, Richards *et al* 2002a, Ruston & Clayton 2007, Schoenberg *et al* 2003, van Tiel *et al* 1998). Richards and colleagues (2002a) found that women were often concerned that reporting chest pain may be wasting doctors' time and, although both women and men sought advice from other people, women were less likely to be directed towards medical care. Zuzelo (2002) found that women tended to deal with other family responsibilities before seeking medical help. Even when women had sought medical help, Foster and Mallik (1998) noted that men tended to be admitted to hospital more quickly than women.

With regard to gender differences in symptoms experienced, studies have suggested that there are more similarities than differences in the way women and men described their symptoms (Vodopiutz and colleagues 2002, Zuzelo 2002). Studies that only involved women (Arslanian-Engoren 2005, 2007, Dempsey *et al* 1995, Holliday 2000, Lockyer 2005, McSweeney 1998, McSweeney *et al* 2000, 2001, 2005, Miller 2000, Rosenfeld & Gilkeson 2000, Ruston & Clayton 2007, Schoenberg *et al* 2003) and a study that only involved men (White & Johnson 2000) also suggest that the gender difference in symptom identification is more significant than gender differences in symptoms experienced.

Richards and colleagues (2002b) found that low socio-economic status is also implicated in the likelihood of delay. They largely attributed this to people from deprived areas having greater exposure to ill health and subsequently being more likely to confuse their symptoms with other conditions. They also found that self-blame and fear

of blame appeared to contribute to a reluctance to seek care, which was more common in patients from socially deprived areas (Richards *et al* 2003). Some people are also worried about “bothering” the doctor unnecessarily if their symptoms are not found to be cardiac in origin (Pattenden *et al* 2002, Richards *et al* 2002a).

2.4.2 Perceptions and experiences of CHD

Eighty-two papers arising from seventy-two studies were found that were concerned with patients’ perceptions and experiences of CHD. Many of these studies concern the recovery process following a heart attack, although some have concerned the experiences of angina patients or patients who have undergone surgical procedures, such as coronary artery bypass grafting (CABG). The majority of studies included both men and women participants, although some studies focused exclusively on the experiences of women, men, or patients from ethnic minority backgrounds. One finding in particular that was reported by virtually all of the studies is that having an acute CHD-related event usually causes patients considerable fear and anxiety that they may have another (fatal or severely debilitating) acute event at any time. This is often coupled with sadness or depression over loss of their previous good health, which may remain for months afterwards.

Many of the studies of patients after a heart attack describe the process of recovery as having a number of components, of which the four stages of regaining a sense of control described by Johnson and Morse (1990) are particularly detailed. For this reason their model of adjustment is used here as a framework to describe other studies around. Their first stage is “defending oneself” against a threatened loss of control, which broadly corresponds to the process of making the decision to seek medical help

for the symptoms of heart attack. However, they noted that this initial stage of trying to maintain control often continues while the patient is in hospital, in ways such as patients using humour to minimise the seriousness of the situation, disobeying orders to stay in bed, or concealing the re-occurrence of chest pain. White (2003) described “banter” between patients and nursing staff as a way to reduce the tension, whilst Scherck (1992) reported that patients often tried to “keep a sense of humour”, “think positively” or “keep the situation under control”. Schwartz and Keller (1993) found that some patients were hesitant to report re-occurrence of chest pain to the nursing staff, preferring to wait to see if it spontaneously resolved.

Johnson and Morse’s (1990) second stage of recovery is “coming to terms” with having had a heart attack. This firstly involves “facing one’s mortality”, which was reported by other studies as “not taking life for granted”, gratitude for having survived, or fear of impending death (Johansson & colleagues 2003, Keaton & Pierce 2000, Wiles 1998, Wiles & Kinmonth 2001). Another component of this stage of recovery is making sense of why the heart attack happened, or looking for causes. This was a finding reported by virtually all of the papers that concerned patients who had had a heart attack. The most commonly perceived causes were stress, heredity and aspects of lifestyle, such as smoking, poor diet and lack of exercise. Stress in particular was reported as major perceived cause by a lot of studies (Bergman & Bertero 2001, 2003, Clark 2003, French *et al* 2005, King 2002, Kristofferzon *et al* 2007, MacInnes 2005, Murray *et al* 2000, Sjöström-Strand & Fridlund 2007, Treloar 1997, Webster *et al* 2002, Woodward *et al* 2005). Furze and colleagues (2001) similarly found that stress was commonly perceived as the cause of stable angina.

Another aspect of the process of making sense of why the heart attack happened is reinterpretation of events leading up to the heart attack, which Cowie (1976) described as “retrospective reconstruction”. French and colleagues (2005) found that patients often thought that their heart attack had been triggered by a life event, which allowed them to explain why their heart attack happened when it did. Other studies found that patients often gave very detailed stories of events leading up to and during their heart attack, indicating that they had thought a lot about the causes and had rehearsed the story of the heart attack many times (East et al 2004, Gassner et al 2002, Hutton *et al* 2008, Levy 1981).

Numerous studies found that patients had not thought of themselves as being particularly at risk of heart attack. Wiles (1998) described the lay epidemiology involved in patients’ surprise at having survived a heart attack rather than the popular perception of collapsing and dying, which was also reported by Treloar (1997). Wiles (1998) noted that patients commonly viewed their heart attack as “mild” because they had survived (despite it having been a very definite life-threatening event in some cases), as opposed to a “severe” heart attack resulting in death. Roebuck and colleagues (2001) found that some patients felt angry that they had had a heart attack, particularly if they had followed health recommendations. Jensen and Petersson (2003) found that some patients felt guilt and self-reproach because of their lifestyle prior to their heart attack, whilst Sutherland and Jensen (2000) found that some patients felt that other people blamed them for having a heart attack.

Other components of Johnson and Morse’s (1990) second stage of recovery are termed “facing limitations” and “considering the implications of the heart attack on the future”.

Scherck (1992) and Hutton and colleagues (2008) noted that some patients were concerned about the prospects of being invalids, whilst Bergman and Bertero (2001, 2003) found that many patients felt that life would “never be the same again”, whilst Doiron-Maillet and Meagher-Stewart (2003) found that many patients expressed feelings of loss. Virtually all of the studies noted patients’ residual fear and anxiety, especially of having another (fatal) heart attack. Daly and colleagues (1999), and Webster and colleagues (2002) noted religious fatalism among some patients, in that they expressed that God would decide the time of their death. However, Wiles (1998), and Wiles and Kinmonth (2001) found that patients who did not experience any further chest pain were often surprised at their apparent speed of recovery, and expressed feelings of being a “fraud” for still being looked after several days later. Similarly, Treloar (1997) noted that some patients had felt that they were “malingerers” when required to stay in hospital. Jackson and colleagues (2000) found that in the first week after discharge from hospital many women felt that they had “weathered the storm” but were fearful and anxious, and concerned about the implications of their heart attack on their normal roles and pastimes. By the third week after discharge most patients expected that they would go on to recover fully, although many patients still expressed some residual fear.

The third stage of Johnson and Morse’s (1990) stages of recovery is “learning to live”. This involves patients negotiating an uncertain process of adjustment and regaining trust in their abilities. Daly and colleagues (1999) and Hutton and colleagues (2008) noted that patients often felt that this process was a matter of willpower. Patients often emphasised this by the use of phrases such as “winning the battle” and other military metaphors. Murray and O’Farrell (2000) found that there was a focus on resiliency in

their study of older female patients, for whom maintaining functional capacity was a priority.

A crucial step in the adjustment process is “preserving a sense of self”, since Johnson and Morse (1990) noted that many patients felt that physical limitations reduced their sense of self-worth. This is supported by a lot of other studies that reported that patients often had physical limitations, most commonly tiredness, chest pain or breathlessness, and subsequently felt frustrated, depressed, angry, tearful and easily irritated (Ford 1989, Hutton *et al* 2008, Jackson *et al* 2000, Jensen & Petersson 2003, Johansson *et al* 2003, Keaton & Pierce 2000, Kristofferzon *et al* 2007, Roebuck *et al* 2001, Shih & Shih 1999, Stewart *et al* 2000, Sutherland & Jensen 2000, White *et al* 2007, Wiles 1998). Jensen and Petersson (2003) described this as being “locked up in a sickness role”, whilst Roebuck and colleagues (2001) noted that some patients were too fatigued to go to see friends easily and felt lonely and isolated as a result. They also found that breathlessness and chest pain caused fear, to the point where some patients were afraid to exert themselves at all. Johnson and Morse (1990) noted that patients were concerned that others would see them as weak or incapable and hence attempted to “put the record straight” by exerting themselves more than recommended.

Another component of this third stage of recovery was termed “minimising uncertainty”, which involves patients gauging their progress, sometimes by comparing themselves to others, seeking reassurance, learning about their health and being cautious to avoid over-exertion. Various aspects of this were reported by other studies: Gambling (2003) found that patients often compared themselves to others, whilst Higgins and colleagues (2000) found that patients thought of their recovery as being either “good” or “bad”,

based on the absence of chest pain and improvement in well-being and energy levels. White (2003) observed that men often used conversation with the nursing staff about the monitors on the Coronary Care Unit as an indirect way to find out about their health status or gauge their progress. This was because conversation about the technology was used to manoeuvre the conversation around to the significance of the readings for them, so avoiding asking direct questions.

Crane (2001) found that the older women in her study used four ways of acquiring knowledge about their health after a heart attack: previous learning; awareness of symptoms or self-knowledge; actively seeking information; and being provided with information by others. However, a number of studies (for example Karner *et al* 2002, 2003, Lisk & Grau 1999,) found that although most patients reported that they had wanted information about their health, they seemed to have a limited understanding about their illness when interviewed. Similarly, Haugbolle and colleagues (2002a, 2002b) reported that a third of stable angina patients claimed to know “nothing” about angina, whilst Furze and colleagues (2001) reported limited medical knowledge in nearly half of their stable angina participants.

The final component of Johnson and Morse’s (1990) third stage of recovery is “establishing guidelines for living”, which involves testing limitations, learning to read their bodies, and lifestyle modification. Several other studies reported that patients tested the limits of their ability (Ford 1989, Doiron-Maillet & Meagher-Stewart 2003, Shih & Shih 1999). Johnson and Morse (1990) also found that there was apprehension about resuming sexual activity, which was also reported by LaCharity (1999) in her study of women.

Johnson and Morse's (1990) fourth stage of recovery after heart attack is "living again", which is the point where, without forgetting that they had had a heart attack, patients are able to put it behind them and allow other areas of their life to take precedence. This stage involves patients accepting their limitations, sometimes expressed as "slowing down". However, Johnson and Morse (1990) found that some patients were unable to adjust after their heart attack and in these cases there was a sense of "abandoning the struggle". Lidell and colleagues (1998) found that there was a tendency for these sort of emotional problems to be related to emotional vulnerability prior to the heart attack, such as insecurity, lack of intimacy, anxiety, or feelings of inferiority. Other studies found that fatalism, especially connected to religion, was linked to some patients' apparent lack of motivation to recover (Keaton & Pierce 2000, Webster *et al* 2002).

A number of studies exclusively concerned the experiences of women, or focused on gendered aspects of recovery after a heart attack. Emslie (2005) argues this has done much to redress the earlier tendency in the literature to generalise from male experience to human experience in general. These studies found a number of issues specific to women. Heart attacks are popularly believed to be a "man's disease" and several studies found that subsequently some women had difficulty identifying the cause of their heart attack (Doiron-Maillet & Meagher-Stewart 2003, Johnson & Morse 1990, Kerr & Fothergill-Bourbonnais 2002, LaCharity 1999). LaCharity (1999) found that age and gender may result in delay in diagnosis for younger women, whilst other studies found that some women felt that men, including doctors, did not always take their health complaints seriously (Odell *et al* 2006, Thomas 1994). Many studies reported that women commonly experience tension between their various roles (as

mother, wife, worker, and care provider), and their own needs for support and independence after a heart attack (Fleury *et al* 1995, 2001, Helpard & Meagher-Stewart 1998, Kerr & Fothergill-Bourbonnais 2002, Kristofferzon *et al* 2003, 2007, LaCharity 1997, 1999, Plach & Stevens 2001, Sjöström-Strand & Fridlund 2007, Thomas 1994, Tobin 2000, White *et al* 2007). As such, they often feel guilty about the reduction in their care-giving role or for putting themselves first, and may try not to be a “burden”.

Gender-based differences have also been reported in the coping mechanisms employed after a heart attack, in that women tend to share their experiences and feelings with other women, whereas men tend not to (Doiron-Maillet & Meagher-Stewart 2003, Fleury *et al* 1995, 2001, Kristofferzon *et al* 2003, LaCharity 1997, 1999, Lisk and Grau 1999, Tobin 2000). Lisk and Grau (1999) found that for some women this avoided burdening family members, whilst Kerr and Fothergill-Bourbonnais (2002) found that elderly women often used their ability to socialise as an indicator of their progress towards recovery.

The tendency in the literature towards solely focusing on patients who have had a heart attack has been criticised (Clark *et al* 1998), although there has since been a tendency towards studies including a greater variety of CHD patients. This has resulted in some studies seeming to view their sample as a homogenous group, and therefore failing to determine findings that are specific to particular groups of CHD patients, such as those who have undergone CABG.

Of those studies that included CABG patients, fear of dying during surgery, and subsequent relief and gratitude at having survived were common themes (Hunt 1999,

Lindsay *et al* 2000, Radley 1996, Treloar 1997, White Robinson 2002). As such, many patients viewed the operation in terms of the possibility for either “cure” or death. Similarly, studies have found that many patients who had had a CABG described themselves as “cured”, “mended” or “fixed” (Keller 1991, Lindsay *et al* 2000, Lisk & Grau 1999). However, Treloar (1997) found that patients who had had a CABG described being constantly aware of their heart problems, unlike patients in her study who had had a heart attack. Treloar (1997) also reported that because CABG patients tended to be in hospital longer than heart attack patients, there was a greater opportunity for them to see others at different stages of recovery, which gave them and their family some idea of what to expect. Similarly, Radley (1996) found that many CABG patients sought reassurance that they were making a “normal” recovery, whilst Plach and Stevens (2001) found that the women in their study judged their health by the presence or absence of symptoms after surgery. Hawthorn (1993) reported that women may see the surgical scar as a sign of mutilation and a threat to their identity, whereas men are more likely to view this it as a “badge of courage”. She noted that women reported more discomfort at the scar site than men, although Treloar (1997) found that many CABG patients report this, irrespective of gender.

Another important factor in patients’ recovery from acute CHD-related events is social support, which patients often get from CR programmes and self-help groups (Bergman & Bertero 2001, Hildingh *et al* 1995, 2006, Lisk & Grau 1999, Rosenfield & Gilkeson 2000, Shih & Shih 1999, Treloar 1997). In these studies patients often reported reduction in stress through sharing and comparing their experiences with other members of the group and health professionals (Hildingh *et al* 1995, Lisk & Grau 1999, Rosenfield & Gilkeson 2000). However, the bulk of the social and emotional support

given to patients recovering from acute CHD-related events comes from their partners (Hildingh *et al* 1995, 2006, Roebuck *et al* 2001, Stewart *et al* 2000, Thompson *et al* 1995, Treloar 1997) or friends and relatives for those who are unpartnered (Rankin *et al* 2002). Several studies reported that as a result of an acute CHD-related event, patients had developed closer, more supportive relationships with their partners (Ford 1989, Radley 1996, Thompson *et al* 1995, Treloar 1997). On the other hand, Svedlund and Axelsson (2000) noted that their women participants often withheld their feelings of fear and vulnerability and did not talk about them with their partners.

A lot of studies reported that patients often felt that their partners or family members were being over-protective. Jensen and Petersson (2003) described this as being “wrapped up in cotton wool”, whilst Thompson and colleagues (1995) suggested that this is an expression of guilt or a manifestation of partners’ need to manage their own anxiety. This may lead to the partner taking a more dominant role in their relationship, which may not always be welcome (Goldsmith *et al* 2006, Hogg *et al* 2007, Jensen & Petersson 2003, Odell *et al* 2007, Patterson 1989, Sjöström-Strand & Fridlund 2007, Stewart *et al* 2000, Tapp 2004, Thompson *et al* 1995, White *et al* 2007). Nagging has been reported as a particular example of this (Goldsmith *et al* 2006, Tapp 2004).

2.4.3 Perspectives on treatment of CHD

Although not strictly ‘treatment’, behavioural changes are widely regarded as functionally equivalent to ‘therapeutic interventions’ and incorporated into the professional remit of advice and intervention, especially in national standards and guidance on CHD (Department of Health 2000). As such, both drug therapy and lifestyle modification are subsumed within the term ‘treatment’ of CHD in this thesis.

Two papers were found that focused exclusively on aspects of patients' perspectives on lifestyle modification (Condon & McCarthy 2006, Karner *et al* 2005). In addition, a number of published reports arising from studies that focused on the nature of the experience (especially of having a heart attack), the process of recovery or patients' perspectives on their recovery included findings that concerned patients perspectives on lifestyle modification (e.g. Bergman & Bertero 2001, East *et al* 2004, Ford 1989, Gambling 2003, Jensen & Petersson 2003, Johnson & Morse 1990, Kerr & Fothergill-Bourbonnais 2002, LaCharity 1999, Plach & Stevens 2001, Roebuck *et al* 2001, Tolmie *et al* 2006, Treloar 1997, Wiles 1998, Wiles & Kinmonth 2001). From these studies, two broad themes seem evident. Firstly, some patients, but typically not all patients, make and maintain some lifestyle changes but not necessarily all of the changes recommended (Bergman & Bertero 2001, East *et al* 2004, Ford 1989, Gambling 2003, Jensen & Petersson 2003, Roebuck *et al* 2001, Tobin 2000, Tolmie *et al* 2006, Wiles 1998, Wiles & Kinmonth 2001). Secondly, patients often experience difficulty in making and maintaining lifestyle changes (Bergman & Bertero 2001, Boutin-Foster 2005, Condon & McCarthy 2006, Gambling 2003, Karner *et al* 2005, LaCharity 1997, 1999, Plach & Stevens 2001, Sjöström-Strand & Fridlund 2007, Thomas 1994, Tobin 2000).

Studies have reported that patients may perceive that lifestyle change is needed to prevent further heart attacks (Condon & McCarthy 2006, East *et al* 2004, Fleury & Sedikides 2007, LaCharity 1999, Jensen & Petersson 2003, Johnson & Morse 1990, Scherck 1992, Treloar 1997). Studies have also found that the way patients made sense of their heart attack appeared to influence their decisions about making lifestyle changes (Jensen & Petersson 2003, Johnson & Morse 1990, MacInnes 2005, Ononeze *et al* 2006, Thomas 1994, Wiles 1998, Wiles & Kinmonth 2001). Subsequently, patients

who were unable to find a lifestyle cause for their heart attack had difficulty in committing themselves to and maintaining lifestyle modifications (Bergman & Bertero 2001, Gambling 2003, Jensen & Petersson 2003, Johnson & Morse 1990, MacInnes 2005, Thomas 1994).

Several studies have found that patients appeared to view lifestyle changes in terms of leading to improvements in their health or getting 'back to normal' (Berman & Bertero 2001, Johnson & Morse 1990, Tobin 2000, Wiles 1998, Wiles & Kinmonth 2001). Johnson and Morse (1990) and Tobin (2000) found that patients discontinued changes that did not result in health improvements. Wiles (1998) and Wiles & Kinmonth (2001) noted that two weeks after a heart attack, patients' expectations of getting 'back to normal' in approximately three months were influenced by the generalised information given, which suggested that most people did get 'back to normal' in this time frame. They noted that patients viewed lifestyle modification in terms of getting 'back to normal', rather than being long-term preventative measures. Second interviews with these patients four months after their heart attack indicated that patients who had got 'back to normal' now tended to view lifestyle modifications as being long-term preventative measures because they perceived themselves as being "vulnerable" to heart attacks but had low motivation to maintain lifestyle modifications because they had got 'back to normal'. Some patients now questioned the relevance of maintaining lifestyle modifications by contrasting it with their observations about people who were similar to the coronary candidacy caricatures of "Uncle Norman" or "The Last Person" (you'd expect to have a coronary) as described by Davison and colleagues (1991). Patients who had not recovered as much as they had expected continued to view lifestyle modification in terms of recovery. Some patients continued with lifestyle

changes in the hope that this might eventually lead to recovery, whilst others viewed lifestyle modification as being pointless (Wiles 1998, Wiles & Kinmonth 2001).

Studies have also drawn attention to the difficulties that patients often have in making and maintaining lifestyle changes. LaCharity (1999) found that patients reduced the difficulty of maintaining dietary changes by making “planned exceptions”, whilst Kerr and Fothergill-Bourbonnais (2002) found that some older patients used “cheating” as a way of regaining control over their lives. LaCharity (1997) found that older women experienced difficulty because of food cravings and a lack of interest in preparing meals. Gambling (2003) found it common for patients to become resentful of the restrictions on their lifestyle and temporarily give up. She highlighted the difficulty many patients have with giving up smoking and noted that the effort required made it difficult for patients to focus on other areas of their lifestyle (e.g. because of snacking to ward off nicotine cravings), as was similarly found by Condon & McCarthy (2006). Studies have found that patients may find maintaining regular physical exercise difficult because of a dislike of exercise, poor weather or experiencing symptoms (LaCharity 1999), that patients perceive the recommendations to be unrealistic and “asking too much” (Gambling 2003), or lack of access to facilities to exercise (Karner *et al* 2005). Studies have found that some patients perceive there to be too many changes to make at once (Condon & McCarthy 2006, Gambling 2003). Gambling (2003) found that as a result patients often overcompensated in one area of lifestyle modification to make up for failing to modify another.

Some studies noted gender differences in the lifestyle modifications made, for example that men tended to see lifestyle modification as a joint venture with their partner

(Johnson & Morse 1990, Stewart *et al* 2000, Treloar 1997) whilst women tended to make lifestyle modifications independently and were reluctant to make changes that might disrupt the whole family routine (Gambling 2003, Johnson & Morse 1990). Studies have found that women tended to view exercise primarily in terms of losing weight and keeping fit and mobile rather than in terms of CHD prevention (Ruston & Clayton 2002, Sriskantharajah & Kai 2007). It has also been found that women tended to perceive that the activity inherent in their domestic lives provided moderate physical activity, which was considered to be best since over-exercising was considered potentially harmful (Clayton & Ruston 2003, Sriskantharajah & Kai 2007).

Research has also pointed to insufficient information being given to patients about lifestyle modification (Crane 2001, Gambling 2003, Thomas 1994, Webster *et al* 2002) or found that they have insufficient knowledge to be able to make lifestyle changes (Bergman & Bertero 2001, Condon & McCarthy 2006, Karner *et al* 2002, 2005). For example, studies have found that patients were aware that they needed to reduce their fat intake but they were often not sure about exactly what they should be eating (Bergman & Bertero 2001, Crane 2001, Gambling 2003). Inadequate provision of appropriate information may be a particular problem for certain groups of patients, such as those from ethnic minority backgrounds (King *et al* 2006, Sriskantharajah & Kai 2007, Webster *et al* 2002). For example, Webster and colleagues (2002) found that the Gujarati Hindu patients they interviewed had been given little information about lifestyle modification. Few had read the leaflets they had been given, which may in part have been because they were unable to understand them because they were in English. None of the patients were doing regular physical exercise and cutting down on spicy food was the only lifestyle change that was frequently mentioned. Gambling (2003)

pointed out that a particular problem for patients was that information was generalised, such that “everyone received the same instructions” rather than being tailored to their individual needs. Subsequently, patients decided for themselves what information was relevant to them. Other studies found that patients had taken a proactive role in seeking information about lifestyle modification (Crane 2001, Lisk & Grau 1999, Treloar 1997).

Fewer studies were found that reported findings about patients’ perspectives on medicines for CHD than reported findings about lifestyle modification (Attebring *et al* 2005, Bergman and Bertero 2001, Crane 2001, Haugbolle *et al* 2002a, 2002b, Karner *et al* 2002, MacDermott 2002, Ononeze *et al* 2006, Roebuck *et al* 2001, Tolmie *et al* 2006, Treloar 1997, Wiles & Kinmonth 2001). Few of these studies seemed to have explored patients’ perspectives on taking medicines in depth and only one study was found that explored whether patients’ perspectives changed over time (Wiles & Kinmonth). This study looked at the early recovery period after a heart attack (i.e. around the time that CR patients are likely to have completed the programme). They noted that unlike patients’ perspectives on lifestyle modification, their perspectives on taking medicines appeared to be “more stable” since they had not changed by the second interview and none of the patients had considered stopping their medication. Karner and colleagues (2002) reported that “most patients expressed that they adhered to the drugs prescribed”. Ononeze and colleagues (2006) found that “all reported positive attitudes and good adherence to medicines” in a group of patients who had either got stable angina or had had a heart attack at least eighteen months prior to the study. MacDermott (2002) reported that stable angina patients “reluctantly complied” with their medicines even though most would have ideally preferred not to take medicines. In contrast, Haugbolle and colleagues (2002a, 2002b) found that a quarter

of their stable angina patients altered or omitted doses and half of the patients occasionally forgot to take their medicines. Similarly, Crane (2001) found that some patients self-regulated their medicines, such as taking extra doses of diuretics when their ankles swelled up. Tolmie and colleagues (2006) found that “a number of patients did not follow their recommended medication regimen” in a group of patients who had had CABG surgery seven years prior to the study.

Haugbolle and colleagues (2002a, 2002b) reported that the reasons that stable angina patients gave for dosage alteration or omission included fear of dependency, dislike of medicines and experiences of side effects. Some patients altered or omitted doses in response to symptoms but there was a greater tendency toward omission of doses because of negative feelings toward medicines. In contrast, MacDermott (2002) found that stable angina patients did take their medicines despite experiencing side effects. Tolmie and colleagues (2006) found that reasons CABG patients gave for not taking their medicines included that some patients had not wanted to “go back down that road again”, whilst others were not convinced that their diagnosis was accurate or that the medication was necessary. Some patients did not take their medicines because of their concern about the potential for side effects or because they had experienced side effects. Other studies have reported patients’ concern about medicines without linking this to not taking medicines as prescribed. This included concern about side effects (Attebring *et al* 2005, Bergman & Bertero 2001, Johansson *et al* 2003, Karner *et al* 2002, Roebuck *et al* 2001) as well as that patients perceived medicines to be an “intrusion on their daily life” and were concerned about having to take them for the rest of their lives (Attebring *et al* 2005) or that some patients disliked taking medicines (Attebring *et al* 2005, Roebuck *et al* 2001).

Studies have reported that some patients viewed medicines in terms of preventing another heart attack (Attebring *et al* 2005, Ononeze *et al* 2006), delaying progression of CHD (Treloar 1997) or preventing “something serious happening” (MacDermott 2002). In contrast, Karner and colleagues (2002) found that few patients viewed medicines in terms of risk reduction. Wiles and Kinmonth (2001) reported that patients commonly said that stopping medicines without their doctor’s agreement might be dangerous and so appeared to view taking medicines as under the control of doctors. Bergman and Bertero (2001) reported that patients perceived drugs as a help to recover and had wanted to know why their medicines had been prescribed, whilst Treloar (1997) reported that some patients said that their doctor could have been more informative about the reasons for prescribing medicines and some had subsequently consulted a pharmacist. Roebuck and colleagues (2001) reported that patients had wanted to know more about their medication but had received conflicting information. However, studies have also found that either some or many patients did not know what medicines they were taking or how the medicines work (Haugbolle *et al* 2002a, 2002b, Karner *et al* 2002, Roebuck *et al* 2001, Wiles & Kinmonth 2001). In short, these studies suggest that there is no clear link between adequate provision of information, patients’ understanding, and the likelihood of them making or maintaining lifestyle changes or continuing to take medicines.

2.5 Perspectives on health service provision for CHD

Thirty studies (and thirty papers) specifically explored patients’ perspectives on health service provision for CHD. A number of these studies explored patients’ perspectives on CR, whilst other studies concerned patients’ perspectives on health service provision for CHD more generally.

Clark and colleagues (2004, 2005) found that patients who attended the CR programme often reported increased trust in their bodies, greater knowledge of their physical limits, and a heightened sense of fitness. They noted that patients benefited from group camaraderie and the opportunity to compare their progress to others, as was found by other studies (Murie *et al* 2006, Wingham *et al* 2006). Some patients reported being reluctant to leave at the end of the programme, which supports Kacen's (1999) finding of a temporary increase in anxiety in many patients at the end of the CR programme. Clark and colleagues (2004) noted that most patients viewed CR as being predominantly about exercise, which was also found by Hird and colleagues (2004). Several studies found that other components of CR that patients tended to perceive as important included advice, reassurance and psychological support (Day & Batten 2006, Higginson 2006, Tod *et al* 2002, Wingham *et al* 2006).

A number of barriers to patients attending CR were found, of which transport difficulties were a commonly cited barrier (Caldwell *et al* 2005, Cooper *et al* 2005, Hird *et al* 2004, McSweeney & Crane 2001, O'Driscoll *et al* 2007, Paquet *et al* 2005, Tod *et al* 2002). Several studies found that a number of patients felt embarrassed about exercising in public (Clark *et al* 2004, Cooper *et al* 2005, Tod *et al* 2002), although Clark and colleagues (2004) noted that many of these patients reported that their embarrassment had lessened through attendance at CR. Wingham and colleagues (2006) found that some patients disliked the group-based format and preferred home-based CR. Patients' understanding of the cause of their heart attack was also cited as a potential barrier to attendance at CR (Cooper *et al* 2005, Tod *et al* 2002).

Additional issues included limited resources restricting CR service capacity (Paquet *et al* 2005, Tod *et al* 2002) or quality (Day & Batten 2006, O'Driscoll *et al* 2007). Tod and colleagues (2002) found waiting lists of up to twelve months in some cases and that patients were often unable to access information about the availability of CR, especially those patients who did not speak English or who used sign language. Many studies noted low attendance at CR among women and the elderly. McSweeney and Crane (2001), for example, found that nearly half of the women in their study had not been offered CR, and just over a quarter had actually attended. Several studies noted that family responsibilities were a particular barrier to women attending CR (Caldwell *et al* 2005, Hird *et al* 2004, McSweeney & Crane 2001, Tod *et al* 2002).

Several studies concerned patients' perspectives on health service provision for CHD more generally. A common finding was that patients often reported that they had not been given enough information, and that the information they had received was not personalised to them (Hanssen *et al* 2005, Henriksen & Rosenqvist 2003, Kennelly & Bowling 2001, McCallum & Lindsay 2001, Murie *et al* 2006, Netto *et al* 2007, Richard *et al* 2005, Yamanda & Holmes 1998). Some groups of patients seemed to be at a particular disadvantage, such as the elderly (Kennelly & Bowling 2001), patients from areas of socio-economic deprivation (Garner & Chapple 1999), and patients from ethnic minority backgrounds (Netto *et al* 2007, Webster 1997). Several studies sought patients' perspectives in order to evaluate and improve health services provided in CHD. These included a rapid-access chest pain clinic (Price *et al* 2005), nurse-led secondary prevention clinics in GP surgeries (Wright *et al* 2001), consultations with cardiologists about invasive cardiac procedures (Ferguson *et al* 1998, Gordon *et al* 2005, Leahy *et al* 2005) and clinical trials (Agard *et al* 2001, Gammelgaard *et al* 2004).

2.6 Summary

There has been a huge interest in exploring lay perspectives on CHD in recent years, which reflects the growing interest in the use of qualitative techniques in health services research more generally. Over fifty percent of the papers in this review have been published since 2002 (the year this study started). There are now a substantial number of published papers on lay perspectives on CHD and a review such as this cannot completely do justice to the complexity and richness of the findings. Subsequently, the intention here was to highlight key similarities, differences and gaps in the literature.

The key similarities found in the literature concerned several topics. These were lay perspectives on the risk of CHD, their responses to acute CHD-related events, patients' experiences of recovery from acute CHD-related events, their perspectives on treatment, and their perspectives on health services for CHD, especially CR. The findings of studies often concerned more than one of these topics, although fewer studies reported findings on patients' perspectives on treatment for CHD than the other topics. Subsequently, there are gaps in the literature that are of particular relevance to this study. Few researchers seem to have explored whether patients' perspectives on lifestyle modification change over time and little research was found that explored patients' perspectives on taking medicines for CHD, especially whether their perspectives change over time. This provides support for the aim of this study, which is discussed further in section 3.3.1 after aspects of methodology have been discussed.

Chapter Three

Methodology and methods

3.1 Introduction

In this chapter the methodology and methods used in this study are discussed. This begins in section 3.2 with a discussion of theoretical considerations relevant to the choice of a qualitative approach and the use of in-depth interviews. This is followed by a discussion of issues concerned with quality in qualitative research and reflexivity. The use of the broad principles of grounded theory as a practical approach to this study is then discussed.

In section 3.3 the methods used in this study are discussed in detail, starting with a discussion of the aims of the study. This leads into a discussion of ethical approval, patient recruitment, data collection, data analysis and confidentiality. In section 3.4 the key points are reiterated as a summary of the chapter.

3.2 Methodology

3.2.1 Choice of research methodology

The use of qualitative approaches is becoming common in health services research as it is increasingly accepted that a range of methodologies are required to investigate the complexity of health services provision and use (Britten et al 1995, Dingwall 1992, Green & Britten 1998, Pope & Mays 1993, 1995, Smith 2002). This reflects a growing awareness that complex socio-economic and psychosocial factors are involved in the

provision and use of health services, which cannot be satisfactorily explored by using quantitative methods, such as questionnaire survey methodology, alone (Young & Jillings 2000). It has been argued that in part this is because questionnaire survey respondents are typically required to answer a series of specific questions by selecting from predefined options, which limits the range of answers that can be given and assumes that the full range of possible answers is known (Young & Jillings 2000). In contrast, it has been argued that a qualitative approach can focus on identifying and exploring the range and complexity of the factors involved in the provision and use of health services (Pope & Mays 1993, 1995, Smith 2002).

Qualitative approaches may be used to complement quantitative approaches, for example, in a previously unexplored or poorly understood research area prior to undertaking a quantitative study, or to explore quantitative findings in more depth (Britten et al 1995, Pope & Mays 1995, Smith 2002). However, this does not mean that qualitative research should only be used to complement quantitative research. Entirely qualitative approaches are relatively common and valuable in exploring aspects of healthcare, for example, lay and professional perspectives on health and illness, or the culture and organisation of health services provision (Britten et al 1995, Pope & Mays 1993, 1995).

Whilst there is now a growing acceptance that both quantitative and qualitative methods are important tools in health services research, comparison of the two has been the subject of considerable debate (Britten et al 1995, Green & Britten 1998, Pope & Mays 1993, 1995, Smith 2002). In such debates, qualitative and quantitative approaches have sometimes been presented as mutually exclusive, whereas others point out that

the difference between the two is less easy to define than this view presupposes (Baum 1995, Popay & Williams 1996). As such, it is more important to recognise that the choice of research methodology should depend on the research question (Popay and Williams 1996, Silverman 2000):

“While much is made of the difference between qualitative and quantitative research it is difficult to draw a hard and fast distinction between the two. Moreover, people have sometimes seemed so obsessed with seeing the matter as one of either/ or that it has led them to forget that the methods used should depend on the questions asked in response to a problem, not the other way round.” (Popay & Williams 1996)

The focus of this study was on CR patients’ perspectives on CHD and treatment, especially medicines. This developed from the finding discussed in section 2.6 that there appeared to be very little published research that has explored CHD patients’ perspectives on the use of medicines in depth, particularly CR patients. A qualitative approach to this study was chosen on the basis of being better suited to exploring the range, depth and complexity of patients’ perspectives than a quantitative approach. This involved the use of in-depth interviews as a research technique and the discussion now moves on to consider methodological issues concerned with this technique.

3.2.2 Qualitative interviews

There are a variety of research techniques that may be employed in qualitative research and the choice of technique should depend on the purpose of the study. In this study interviews were chosen on the basis of being a technique that enables individual

respondents' perspectives to be explored and in more detail than may be achieved by using techniques such as focus groups (Smith 2002). Hence, the discussion here focuses on issues concerned with using qualitative interviews.

In relation to selection of participants for interviews, a variety of sampling techniques have been described in the literature (May 2001, Pope & Mays 1995, Smith 2002). These include purposive sampling, where the participants selected are believed to have particular characteristics relevant to the research. Convenience sampling involves selecting participants on the basis of ease of accessibility or willingness to participate in the study (Smith 2002). Theoretical sampling is an iterative technique associated with the grounded theory approach (which is discussed further in section 3.2.5) that involves redefining the ongoing selection of participants in order to test and refine the characteristics of emerging themes (Glaser & Strauss 1967). However, sampling procedures used by researchers may combine elements of more than one technique (Smith 2002), which may make defining sampling procedure by technique problematic.

Qualitative interviews are commonly referred to as being structured, semi-structured or unstructured (May 2001, Smith 2002). However, classifying the interview type according to the degree to which the interview is structured may be misleading, since even apparently unstructured interviews have some structure and could be described as semi-structured. To avoid this problem but to mark a distinction between highly structured interviews in which participants' responses may be brief, the interviews conducted in this study have been described as being in-depth.

The subjects or topics of interest that the researcher intends to cover in in-depth interviews are usually drafted into an interview guide prior to the interview. These topics can then be introduced into the interview as open, non-leading questions so that further questions can then be based on responses given by the participant, usually in order to clarify or explore the reasoning behind the views expressed. The number of topics in interview guides is usually limited to allow the interviewer to be guided by the responses of the participant. A balance needs to be struck so that researchers allow participants to express themselves in their own words and tell their own story, which requires skill on the part of the part of the researcher. Seale (1999) describes this as a “craft skill” as it takes time, practice and reflection on performance to develop.

An important theoretical consideration in using qualitative interviews as a research technique is recognising that they (like all qualitative techniques) are a type of social interaction rather than a research method that provides unproblematic access to social reality. As such, data produced by interviews are socially contingent since they result from the interaction between the interviewee and the researcher. The position taken here acknowledges, in practical terms at least, that this means that knowledge that arises from qualitative research is also socially contingent rather than being objective, and independent of the researcher (May 2001, Seale 1999). This does not mean that qualitative research is singularly unable to provide useful insights into subjective experiences that have wider social relevance but it cannot be assumed that interviews will give unproblematic access to factually accurate accounts of past events and experiences. People’s accounts are likely to vary according to whom they perceive they are giving their account to and presentation of moral worth, for example, may take precedence (Cornwell 1984, Radley & Billig 1996). Hence, factors such as how

participants are selected, the interview location, how the interview is conducted and the status or professional background of the researcher is likely to affect the construction of the data (May 2001, Richards & Emslie 2000, Smith 2002). Consideration of the effect of these factors on the construction of the data is associated with issues relating to the quality of qualitative studies, which this discussion now turns to.

3.2.3 Validity, reliability and generalisability: quality in qualitative research?

There are a variety of views on how to achieve quality in qualitative research, of which the concept of rigour is well known. It may be argued that the rigour of a research study, whether taking a qualitative or quantitative approach, may be achieved through a systematic, reflective and transparent approach to research design, methods of data collection, analysis, interpretation and communication (Mays & Pope 1995). Additionally, it may be argued that there are two other measures of rigour that can be used in qualitative research, which are to achieve a credible and coherent explanation of the research topic (also known as validity), and to produce an account of the methods of data collection and analysis such that another qualitative researcher could reach essentially similar conclusions (also known as reliability) (Mays & Pope 1995, Greenhalgh & Taylor 1997, Smith 2002).

Techniques aimed at achieving validity in qualitative research have included a process known as triangulation, in addition to measures such as careful attention to sampling procedures. Triangulation involves the use of two or more different methods of data collection, the results from which can be compared to assess the extent of corroboration (Glesne & Peshkin 1992, Mays & Pope 2000, Smith 2002). Techniques that have been employed to achieve reliability include assessment of transcripts by

other researchers (inter-rater reliability), or by the interviewees themselves (respondent validation) to compare agreement in themes generated (Glesne & Peshkin 1992, Mays & Pope 2000, Smith 2002).

It is generally acknowledged that the results of rigorous qualitative studies are generally not intended to be applicable to a wider population, as is the case with quantitative research, although this does not necessarily preclude a degree of generalisability. The extent that findings from qualitative studies are thought to be generalisable to situations other than the original research setting is based on similarity of features or circumstances (Mays & Pope 2000).

The difficulty with the concept of rigour is that, despite claims that rigour has been achieved if the above criteria have been met by using techniques such as triangulation, this does not necessarily mean that quality has been achieved. For example, as Morse (1997) argued in relation to inter-rater reliability, another person brought into the research to achieve inter-rater reliability who does not have the researcher's comprehensive understanding of the data (which is required for analysis to progress beyond initial coding) leads to superficiality such that the "research will be perfectly reliable but trivial" (Morse 1997).

This relates to the discussion in section 3.2.2 about the socially contingent nature of knowledge, as this has challenged this view of rigour in qualitative research. If it is assumed that reality is socially contingent then, as techniques borrowed from positivist science where an objective reality is assumed, validity and reliability may be problematic concepts when applied to qualitative research (Mays & Pope 2000, Seale

1999, Tobin & Begley 2004). Others have argued that these criteria are relevant but with revised definitions (Ballinger 2004, Mays & Pope 2000), whilst others have proposed alternative criteria deemed to be better suited to qualitative inquiry (Arminio & Hultgren 2002, Ballinger 2004, Guba & Lincoln 1989, Seale 1999). Perhaps not surprisingly there are numerous alternative criteria for achieving quality in qualitative research, for example, the concept of “goodness” (Arminio & Hultgren 2002) or the concept of “trustworthiness” (Guba & Lincoln 1989). These are complex debates and there is insufficient space in this thesis to discuss the various alternatives in detail, especially as “the clutter of terms and arguments has resulted in the concepts becoming obscure and unrecognisable” (Tobin & Begley 2004).

At the same time, there has been a notable proliferation of articles describing checklists and guidelines as an aid to assess the quality of qualitative research (Barbour 2003b, Chapple & Rogers 1998, Harding & Gantley 1998). Barbour (2003b) argued that the typical bullet-point format of checklists makes them appealing because they “appear to render manageable the complexities of the qualitative research process”. She noted that, as a result of the “newfound respectability” of qualitative methods in health services research, checklists are often used as a brief introduction to qualitative methods for the rapidly increasing number of aspirant qualitative researchers. Whilst this has the advantage of making qualitative research accessible to a wider audience, a major disadvantage is that an uncritical overemphasis on achieving all the requirements on the checklist reduces qualitative research to what Barbour (2003b) termed “technical essentialism”. This situation is not helped by word limits imposed in some journals, which may lead to what Morse (2001) described as “the awfulness of simplification”.

Indeed, there is little agreement on how to achieve quality in qualitative research beyond the stipulation that it should take a systematic, reflective and transparent approach to research design, methods of data collection, analysis, interpretation and communication (Mays & Pope 1995). Reflexivity, which this discussion now turns to, is presented here as a practical approach to achieve this and it is recognised that:

“Research is in a large part a craft skill, learned through personal experience of doing research and from an appreciation of what is good in other people’s research studies. In the last analysis, the quality of qualitative research does not depend on unthinking adherence to rules of method, but exposure to methodological debates can help loosen thoughts that are stuck. A good study should reflect underlying methodological awareness, without this awareness being continually made explicit so that it is a screen obscuring the artefact itself.” (Seale 1999)

3.2.4 Reflexivity: theoretical considerations

Reflexivity is described by Hall and Callery (2001) as “critically examining one’s effect as a researcher on the research process”, or more generally by Mays and Pope (2000) as “the degree to which the effects of the research strategies on the findings are assessed or the amount of information about the research process that is provided to readers”. Viewing the nature of knowledge as being socially contingent (as discussed in section 3.2.2) has generally resulted in greater reflection about the role of the researcher in the research process, which has increased the significance of reflexivity (Seale 1999). This is why reflexivity was considered to be a critical part of this study.

A relevant consideration concerned with reflexivity is in actually “doing it”, as Mauthner and Doucet (2003) point out:

“...the importance of being reflexive is acknowledged within social science research and there is a widespread recognition that the interpretation of data is a reflexive exercise through which meanings are made rather than found...However reflexivity has not been translated into data analysis practice in terms of the difficulties, practicalities and methods of doing it. Instead there is an assumption built into many data analysis methods that the researcher, the method and the data are separate entities rather than reflexively interdependent and interconnected.” (Mauthner & Doucet 2003: emphasis in the original)

As such, it is acknowledged that discussing reflexivity in a separate section to the method is an artificial distinction and it is also recognised that there may be a limit to how reflexive researchers can be, especially at the time of actually doing the research. This is because some influencing factors may only become apparent long after the research study has been completed (Mauthner & Doucet 2003). This issue has also been taken up by and developed by Seale (1999), who argued that:

“The attempt to make methodological decisions available to readers of research reports is one way of enhancing the quality of research, even if the requirement to demonstrate an awareness of all the implicit theoretical assumptions made in the course of a research project seems impossibly demanding...There is no substitute for presenting the evidence that has

led to particular conclusions, giving the fullest possible details about the contexts in which research accounts arise. In the last analysis, writers must then trust in their readers' capacity to make their own judgements."

(Seale 1999)

To this end, discussion now turns to grounded theory since its broad principles were drawn upon as a practical approach to this study, after which the study aims, objectives and methods used are described in detail. Issues concerned with the further practical application of reflexivity in this study are discussed in section 8.6.

3.2.5 Grounded theory

The grounded theory approach was proposed (or in their words "discovered") by Glaser and Strauss (1967) as the description and interpretation of social processes in social interactions in order to generate theory or theoretical statements that are grounded in the data. Glaser and Strauss originally developed the grounded theory approach in the 1960s as an alternative to the dominance of positivist approaches and grand theorising in sociology, where data were collected to test the truth of theoretical propositions. In contrast, their grounded theory approach emphasised the inductive generation of theory from data, or less prosaically that the findings of a study are grounded in the data. This is why grounded theory was used as a practical approach to this study.

The process of grounded theory is characterised by collecting data, such as conducting interviews with relevant participants, from which themes or patterns are identified. This usually involves constructing a coding procedure to group themes into categories. Themes from subsequent interviews are compared with those already identified, which

is a challenging iterative process and a core element of the grounded theory approach known as constant comparison. These characteristics of themes can then be further refined by ongoing data collection in a process known as theoretical sampling. The constant comparison technique is used to compare themes identified from further data collection with those already identified to further refine categories (Charmaz 2006, Glaser & Strauss 1967, Green 1998).

A crucial component of this process is deviant case analysis, which involves detailed examination of any examples that do not fit the emerging themes, in order that resultant explanations can aid refining the characteristics of themes (Charmaz 2006, Pope *et al* 2000). The researcher typically continues to interview participants until no new themes emerge, a point known as theoretical saturation. However, knowing when this point has been achieved is difficult, since every new case might provide a new theme or require modification of existing categories, at least to some degree (Seale 1999).

According to grounded theory, data analysis begins at the same time as data collection, since it is used to direct further data collection through a series of sequential or interim analyses (Charmaz 2006, Pope *et al* 2000, Smith 2002). It is therefore an integral part of the research process and not an activity that only occurs after data collection (Charmaz 2006). The process of analysis is meant to ensure that the findings of a study are “grounded” in the data (Glaser & Strauss 1967).

Grounded theory, as a product of its time, originally referred to an account of the concept of rigour that included validity and reliability (the limitations of this were discussed in section 3.2.3), which may not adequately address reflexive concerns (Hall

& Callery 2001). Charmaz (2006) argued that in the practical application in qualitative research, grounded theory may be best viewed as a “set of principles and practices, not as prescriptions or packages”. Barbour (2003b) pointed out that it is unlikely that anyone uses it in its pure or original form and that:

“Grounded theory is also invoked as a distinct philosophical approach to qualitative research. This can, however, obscure or de-emphasise its practical application. Used in this way grounded theory allows for theory generation, and its strength lies precisely in its non-partisan character, that is, it is amenable to very different and potentially contradictory theoretical paradigms.” (Barbour 2003b)

Similarly, Seale (1999) argued that “qualitative researchers would benefit from retaining a hold on the underlying principles of grounded theorizing, rather than dismissing these as inconsistent with modern sensibilities” since:

“Although grounded theory emerged in an era of scientism, and its more technical explications are sometimes unwelcome reminders of this, the spirit that lies behind the approach can be simply explained, and does not have to be attached to a naively realist epistemology, or indeed to an oppressive urge to force readers to regard its products as true for all time. It demands a rigorous spirit of self-awareness and self-criticism, as well as an openness to new ideas that is often a hallmark of research studies of good quality.” (Seale 1999)

With these points in mind, the practical approach to this qualitative study is described as having drawn on the broad principles of grounded theory. This means that the techniques of constant comparison, deviant case analysis and theoretical sampling were used in order to ground the findings in the data. Description of how this was done is presented in the following sections of this chapter, after the aims and objectives of the study are first discussed.

3.3 Methods

3.3.1 Study aims

The overall aim of the study was to explore CR patients' perspectives on CHD and its treatment using a qualitative approach.

Specifically this involved:

- Obtaining Local Research Ethics Committee (LREC) approval to conduct the study (section 3.3.2).
- Obtaining formal written consent from all participants in the study (section 3.3.3).
- Initially conducting in-depth qualitative interviews with a group of CR patients after they had finished attending the CR programme (i.e. approximately three months after discharge from hospital) (section 3.3.4).

- Conducting further in-depth qualitative interviews with theoretical samples of CR patients, with or without a carer present, to refine or test ideas emerging from the study (sections 3.3.3 and 3.3.4).

The rationale for this aim originated from the author's observation from involvement in CR programmes in various hospitals that patients seemed to want to know more about their medicines and tended to ask questions when offered the opportunity by a pharmacist. In addition, there seemed to be considerable variation in the medicines information given to CR patients. A review of the pharmacy practice research literature on CR found few published studies, none of which had explored patients' perspectives in depth on CHD, medicines or lifestyle modification (i.e. the mainstays of treatment for CHD) (White & Anderson 2005). Furthermore, very little published research that concerned the use of medicines was found in the literature on patients' perspectives on CHD (as was discussed in section 2.4.3 and 2.6), although research that concerned lifestyle modification was found. This established a research interest in CR patients' perspectives on the use of medicines in relation to their perspectives on lifestyle modification and CHD.

As Charmaz (2006) points out, researchers' background assumptions and disciplinary perspectives are a factor in initially forming research interests, which act as points of departure. In this study, background assumptions included that patients' perspectives on CHD and treatment were likely to be influenced by the information they are given and this may have implications for pharmacy practice (particularly for the role of pharmacists in CR). Hence, the point of focusing on CR patients was that information about CHD and treatment is specifically given to patients, which could not be assumed

for all patients with CHD. The reason why a qualitative approach was chosen to explore these interests was explained in section 3.2.1, the decision to use in-depth interviews was explained in section 3.2.3 and the rationale for using the broad principles of grounded theory as a practical approach was outlined in section 3.2.5. This led to formulating the aim of the initial stage of the study. The process of recruitment and interviewing in this initial stage of the study is discussed in detail in sections 3.3.3 and 3.3.4.

The specific aim of the initial stage of the study was to conduct in-depth qualitative interviews with a sample of CR patients after they had finished attending the CR programme to explore their perspectives on CHD and treatment.

Specifically this involved:

- Obtaining LREC approval to conduct the initial stage of the study (section 3.3.2).
- Recruiting a sample of patients attending the CR programme and obtaining their formal written consent to participate (section 3.3.3).
- After they had finished attending the CR programme, conducting in-depth qualitative interviews with this group of patients, with or without a carer or partner present, to explore their perspectives on CHD and treatment (section 3.3.4).
- Continuing to recruit and interview CR patients until saturation had been reached (section 3.3.3).

In section 3.2.5 it was pointed out that the process of data analysis starts at the time of data collection through a series of interim analyses. As such, the development of a study is grounded in the data, and background assumptions and disciplinary perspectives (or “sensitizing concepts” to use Blumer’s (1969) depiction), as Charmaz (2006) points out:

“...provide a place to start not to end. Grounded theorists use sensitizing concepts as tentative tools for developing their ideas about processes that they define in their data. If particular sensitizing concepts prove to be irrelevant, then we dispense with them...Grounded theorists evaluate the fit between their initial research interests and their emerging data. We do not force preconceived ideas and theories directly upon our data. Rather, we follow leads that we define in our data...” (Charmaz 2006: emphasis in the original)

During the initial stage of the study the background assumption that patients’ would view pharmacy service development in CR as beneficial to their treatment did not emerge from analysis of the data, as it seemed that the involvement of pharmacists was seen as peripheral to patients’ perspectives on CHD and treatment. Subsequently, this sensitizing concept was not found to be helpful. On the other hand, an important theme that was emerging from the data concerned how patients’ perspectives on the risk of further CHD-related events were related to their perspectives on treatment, especially lifestyle modification. The significance of this was that all bar one of the patients had had a heart attack and their perspectives on risk seemed to be linked to their fear of

having another heart attack (especially if fatal). This suggested that if they felt less fearful over time, their perspectives on risk, and in turn, treatment may also change.

This was supported by the literature, since qualitative studies (discussed in section 2.4.3) indicated that CR patients may not maintain lifestyle modifications over time (e.g. Gambling 2003, Wiles 1998). Similarly, quantitative studies found that over time patients may not continue to use medicines for CHD (e.g. Burke & Dunbar-Jacob 1995, Kopjar *et al* 2003). However, (as discussed in sections 2.4.3 and 2.6) there appeared to be little research that had explored patients' perspectives in-depth on the use of medicines, especially whether these change over time. As such, exploring whether CR patients' perspectives on CHD and treatment (especially medicines) changed over time became a relevant lead to follow so that the development of the study would be grounded in the data. To do this the CR patients were interviewed again, which was a theoretical sample to test these ideas and in doing so refine the themes emerging from the data. This second set of interviews was conducted with patients nine months after the initial interview (i.e. approximately one year after discharge from hospital) to give a lengthy interval between interviews. The process of recruitment and interviewing in this second stage of the study is discussed in sections 3.3.3 and 3.3.4.

The specific aim of the second stage of the study was to conduct second in-depth qualitative interviews with the CR patients approximately nine months after the first interview to explore any changes in their perspectives on CHD and treatment.

Specifically this involved:

- Obtaining LREC approval to conduct the second stage of the study (section 3.3.2).
- Re-recruiting the sample of CR patients who participated in the initial stage of the study and obtaining their formal written consent to participate (section 3.3.3).
- Conducting in-depth qualitative interviews with this group of CR patients, with or without a carer or partner present, to explore any changes in their perspectives on CHD and treatment (section 3.3.3).

The origins of the third stage of the study focused on one deviant case in the initial sample who had not had a heart attack. Rather, he had had coronary artery bypass grafting (CABG) surgery resulting from a long history of angina. His perspectives on risk and treatment seemed to be different from the other patients who had had a heart attack (including a patient who went on to need a CABG after having a heart attack). In addition, his perspectives on risk did not seem to have significantly changed by the time of the second interview, unlike the other patients. This suggested that his perspectives may have been different to the other patients because he had not had a heart attack (these differences are discussed in more detail in section 7.1). Further theoretical sampling in this third stage of the study was subsequently undertaken to explore the perspectives on CHD and treatment of a group of CR patients who had not had a heart attack. The process of recruitment and interviewing in this third stage of the study is discussed in sections 3.3.3 and 3.3.4.

The specific aim of the third stage of the study was to conduct in-depth qualitative interviews with CR patients who had not had a heart attack in order to explore their

perspectives on CHD and treatment, so that these could be compared with the perspectives of the CR patients who had had a heart attack.

Specifically this involved:

- Obtaining LREC approval to conduct the third stage of the study (section 3.3.2).
- Recruiting a sample of CR patients who had not had a heart attack and obtaining their formal written consent to participate (section 3.3.3).
- After they had finished attending the CR programme, conducting in-depth qualitative interviews with these patients, with or without a carer or partner present, to explore their perspectives on CHD and treatment (section 3.3.4).
- Continuing to recruit and interview patients until saturation had been reached (sections 3.3.3 and 3.3.4) so that the findings could be compared with the previous findings of the study.

3.3.2 Local Research Ethics Committee approval

An application to conduct the initial stage of the study was submitted to the local research ethics committee (LREC) in January 2003. It was stated that approval would be sought for further stages of the study as appropriate. Approval for this stage was granted. Approval for the second and third stages of the study was subsequently sought and obtained. In accordance with the LREC requirements, annual progress reports and a completion of research form have been submitted.

The applications for each stage were accompanied by the Patient Information Sheet, the consent form, the interview guide and other relevant supporting documentation. An example of a Patient Information Sheet is included as appendix one and an example of a consent form is included as appendix two. The interview guide used in stage one is included as appendix three and the interview guide used in stage two is included as appendix four. A letter that was sent to patients in stage three is included as appendix five and the interview guide used in stage three is included as appendix six.

3.3.3 Recruitment of participants

In the initial stage of the study a sample of patients was recruited from the CR programme based at a district general hospital in the east of England. The intention was to recruit a broadly representative sample of CR patients from this programme in order to explore the range of their perspectives on CHD and treatment in depth. However, as was discussed in section 3.2.2, defining sampling techniques in such terms may be problematic because sampling procedures may combine elements of more than one technique (Smith 2002). As such, the sampling technique used could also be described as purposive sampling because patients were selected who shared characteristics that were believed to be most informative in achieving the objectives of the study (e.g. they attended the CR programme). Likewise, the sampling technique used could also be described as convenience sampling because the patients selected were those most willing to participate.

Patients were recruited from the CR programme on a face-to-face basis and, as discussed in section 3.2.2, it is acknowledged that the identity of the researcher amongst other things (including the sampling technique) is highly likely to affect the

construction of the data (this is discussed further in section 8.6). Subsequently, the author introduced himself to patients as a researcher from the University rather than as a pharmacist.

The criteria used in selecting patients for this stage of the study were intended to be as inclusive as possible. As such, all patients who attended the CR programme during recruitment for the initial stage of the study were considered to be eligible to participate, provided that written consent was given. No other exclusion criteria were applied.

Recruitment started in February 2003 and involved the author attending the CR programme and giving a brief presentation to the patients to explain what the research was about and how it might involve them. They were told that the Patient Information Sheet (an example is included as appendix one) explained more about the study and that copies had been left on a table near the door so that they could take a copy if they wished. It was explained that the author would return the following week to see if any of them wished to participate, which allowed them a cooling-off period of at least a week to decide. In addition, they were told that participation was entirely voluntary and their care would not be affected in any way if they chose not to. On successive weeks the author attended the CR programme and gave these brief presentations to inform new patients to the programme about the study and to remind the other patients of what had previously been said. The author then stayed while they were getting ready to go home in order to give them an opportunity to volunteer. Patients were not approached on an individual basis to avoid putting them under any pressure to volunteer.

Formal written consent and a contact telephone number were obtained from all respondents recruited to the study (an example of a consent form is included as appendix two). Each respondent was then contacted by telephone to arrange a location of the patient's choice and a mutually convenient time for the interview. Interviews were held after respondents had finished attending the CR programme. This process of patient recruitment was successful in recruiting ten patients to the study (over a period of three months).

After transcription of these interviews and interim analysis of the data, further recruitment of patients was conducted to saturate the emerging themes. In the first few weeks of the author attending the CR programme again no more patients chose to participate in the study. Subsequently, a change was made to the procedure described above so that Patient Information Sheets were handed out to all new CR patients at the brief presentations. This proved to be more successful and six more respondents were recruited to the study (over a period of three months) to make a total of sixteen.

As discussed in section 3.2.5, the aim of grounded theory approaches is to continue to recruit and interview participants until no new themes emerge, at which point saturation has been achieved. In this initial stage of the study by the time about thirteen interviews had been conducted no new themes appeared to be emerging that related to the topics in the interview guide, which was confirmed by the final three interviews. The decision to cease recruitment was made because it was felt that saturation had been achieved. However, as was pointed out in section 3.2.5, knowing when this has been achieved is difficult, since every new case might provide a new theme or require modification of existing categories (Seale 1999). In this stage a difficult issue related to the under-

representation of women in the sample (four out of sixteen), which seemed to reflect the under-representation of women in the CR programme more generally, rather than there being a greater proportion of women than men choosing not to participate. However, significant gender differences in patients' perspectives did not seem to be apparent in the data, which is why the decision was made to cease recruitment.

In the second stage of the study the intention was to recruit a theoretical sample of patients to test and develop emerging themes, especially concerning whether patients' perspectives on risk of further CHD-related events changed over time and, if so, whether this affected their perspectives on treatment. These patients were selected on the basis of having been interviewed in the initial stage of the study and that they consented to be interviewed again. No other inclusion or exclusion criteria were applied.

The process of re-recruiting the patients for the second stage of the study (which involved second interviews approximately nine months after the initial interview), started by checking hospital computer records to attempt to determine whether any of the patients had died, since if so it was highly likely to have been recorded. This indicated that one of the patients had died. The remaining fifteen patients were contacted in writing to invite them to participate. A Patient Information Sheet and a consent form were enclosed and patients were asked to sign and return the consent form in a reply-paid envelope if they wished to participate. Four patients did not reply so a reminder letter was sent, which none of them replied to. Subsequently, the eleven patients who did reply were re-recruited for second interviews. Each respondent was then contacted by telephone to arrange a location of the patient's choice and a mutually convenient time for the interview.

It is recognised that claiming that saturation was reached in this stage of the study could be questioned on the grounds that further recruitment of patients would have been extremely difficult, which may have led to a premature claim of saturation. However, less variation in perspectives was noted between patients than in the initial stage and no major new themes appeared to be emerging that related to the topics in the interview guide by the ninth interview or after. The decision not to recruit further patients was made on this basis, although deciding whether saturation was actually achieved remains a difficult issue.

As discussed in section 3.3.1, the third stage of the study focused on one deviant case in the initial sample who had not had a heart attack because his perspectives on risk and treatment seemed to be different from the patients who had had a heart attack. In addition, his perspectives on risk had not significantly changed by the time of the second interview, unlike the other patients. Further theoretical sampling in the third stage of the study was subsequently undertaken to explore the perspectives on CHD and treatment of a group of CR patients who had not had a heart attack. For the purpose of analysis the data from this patient was included in the sample of CR patients recruited for this third stage of the study (i.e. at this point the patient was effectively excluded from the initial stage and second stage samples to leave an initial stage sample of fifteen heart attack patients and a second stage sample of ten heart attack patients). The way the data from this patient was handled in the analysis is discussed in section 3.3.4 since this relates to the topics included in the interview guide used in the third stage of the study.

The majority of patients referred to the CR programme at the hospital where the study was undertaken had had a heart attack, although some had also undergone heart surgery. The CR patients who had not had a heart attack were those who had been referred for CR because they had undergone CABG surgery. The CR nursing team maintained a computer database of patients who had attended CR since 2003, where patients were classified according to whether they had had a heart attack or CABG surgery, although the database did not include details of whether CABG patients had previously had a heart attack. Ninety CABG patients were initially selected from this database and medical records were examined to exclude those patients who had previously had a heart attack. Patients were also excluded if medical records could not be accessed or found, or if a home address could not be found. Twenty-eight patients were deemed eligible for inclusion into the study and at this point a telephone call was made to each patient's general medical practitioner (GP) to ensure that the patient had not deceased, which none of them had. No other exclusion criteria were applied.

These twenty-eight patients were sent a covering letter (included as appendix five) inviting them to participate in the study, a Patient Information Sheet and a consent form. A stamped envelope was included so that patients who chose to participate could complete and return their consent form, which included a contact telephone number. Fourteen patients who did reply were contacted by telephone to arrange a location of the patient's choice and a mutually convenient time for the interview. During the interviews one patient was found to have had a heart attack and another was found to be too hard of hearing and short of breath for meaningful conversation. Subsequently these patients were excluded from the sample. Including the deviant case patient from

the earlier stages of the study who was added to this stage, there were a total of thirteen patients in the sample (recruited over a period of two months).

The decision to cease recruitment at this point was made on this basis that by the time eight or nine interviews had been conducted no new themes appeared to be emerging that related to the topics in the interview guide, which was confirmed by the remaining three or four interviews. At this point it was felt that saturation had been reached, bearing in mind the caveat made in section 3.2.5 about the potential for every new case to provide a new theme or require modification of existing categories (Seale 1999).

3.3.4 Qualitative data collection: in-depth interviews

In the initial stage of the study audiotaped, in-depth interviews were conducted with sixteen patients. As was discussed in section 3.2.2, the subjects or topics of interest that the researcher intends to cover in qualitative interviews are usually drafted into an interview guide before the interviews. The interview guide (included as appendix three) was developed to meet the aim of the initial stage of the study, which was to explore CR patients' perspectives on CHD and treatment. As discussed in section 3.3.1, background assumptions (or sensitizing concepts) were involved in initially forming the research interest that led to this aim, and these were included in the interview guide. The topics of interest were formulated as: perspectives on CHD; perspectives on medicines; sources of medicines information; and experiences of pharmacists.

The topic on patients' perspectives on CHD covered what had initially caused the patient to seek medical care, what it was like being in hospital, what happened after discharge from hospital and what the CR programme was like. This topic also covered

issues such as the impact that CHD had had on the patient's life and how they had coped, what it was like to have CHD and their concerns and anxieties about this. Questions about their perspectives on lifestyle modification were included to find out what patients thought about the lifestyle modification recommendations (as discussed in section 1.2), what lifestyle changes they had made and not made, and the reasoning behind their choices. Questions were also included about the information patients had been told about CHD, who had given them that information and what patients thought about the information given.

The topic on patients' perspectives on taking medicines covered whether patients had been taking medicines before having CHD and, if so, what these had been for. Patients were asked what their views about taking medicines were, whether they were taking them as prescribed and if not, what the rationale for this choice was. Questions were included to generate data on how patients' perspectives on medicines were related to their perspectives on CHD. These included asking whether their medication regimen had altered since they had been diagnosed with CHD, and if so what had changed, what they thought about taking these new medicines (e.g. whether or not they had experienced side effects), whether they took the medicines as prescribed and if not what the rationale for this choice was. A question was also included on why they thought the medicines had been prescribed (i.e. their explanatory models of how they thought the medicines worked).

The topic on sources of medicines information was partly included to find out where and how patients had gained their knowledge about their medicines and what they thought about those sources, but also to see if patients would say anything about their dealings

with pharmacists without being specifically prompted. The final topic on their experiences of pharmacists primarily covered the contact they had had with pharmacists, but also what contact they would have liked to have had with pharmacists. The intention in putting the topics in this order was to broadly explore patients' perspectives, rather than just to see if support would be provided for the background assumptions.

This interview guide and the guides used in the other two stages of this study were intended to be used as *guides* only, which is why they were not written as a series of specific questions to be asked. The questions in the guides were intended only to serve as general prompts for the topics of interest and the sort of questions to ask; other questions were often asked that were not specifically in the guide or were asked in a slightly different way to the guide. This was so that patients could talk about their experiences and perspectives as they wished and express themselves in their own words with minimal prompting. Questions were asked at points that flowed from what patients said, generally to clarify or explore the responses given, rather than sticking rigidly to the order in the guide. Where specific issues were not covered these were introduced later on in the interview, which ensured that the topics of interest were covered but allowed issues of importance to interviewees to emerge.

In the initial stage of the study the interview guide was piloted in the first three interviews and it seemed that the data generated was rich and interesting. As it did not seem that extra questions or prompts needed to be added to the guide, the data from these three interviews was not excluded from the sample. However, the approach to the interviews was modified on the basis of these pilots because at the first interview both

the patient and his wife arrived. The wife said that she was interested to know what questions her husband was going to be asked and he agreed with this, so it was decided to interview the patient with his wife present, after having first obtained her verbal consent to participating in the study. It seemed that on some points, discussion between them resulted in him volunteering more information than he might have done if he had been interviewed alone. As a result wives, husbands or carers were included in the interviews at the discretion of the patients (the implications of this are discussed further in section 8.6).

Given the emergent nature of qualitative methods, changes to the interview guide occurred during the process of conducting interviews. As was discussed in section 3.3.1, it was found that patients frequently talked about the risk of experiencing further CHD-related events and it seemed that this was related to their fear of this happening. This became apparent by the time the fifth interview had been conducted and questions were asked about fear or worry in subsequent interviews. It was also found that whilst patients tended to talk a lot about their contact with doctors and nurses, they only tended to talk about pharmacists when prompted and even then only briefly. This became apparent by the time roughly half of the interviews had been conducted and discussion in subsequent interviews became orientated around their experiences of getting medicines-related information from health professionals more generally, rather than focusing on pharmacists.

Eight of the sixteen interviews were conducted at the hospital rather than at the patient's home, which was entirely the patient's choice. A room was used that was close to where the CR programme took place. This room was chosen because it was

private (i.e. the interview would not be overheard or disturbed), had comfortable chairs, was close to a hot drinks machine and was in a part of the hospital that the patients were familiar with. The intention was to provide an environment that was as informal as could be achieved, although it is recognised that the interviews may have been different had they been conducted at the patient's home. This is discussed further in section 8.6.

The interviews generally lasted approximately one hour, although several lasted nearly an hour and a half. After each interview the author reflected and made notes on how the interview had gone and important issues or themes that had emerged. These notes also included any relevant comments made by interviewees before the tape recorder was switched on. The interviews were transcribed verbatim by the author and care was taken in transcribing to ensure that significant pauses (including, as far as possible, interviewees use of "erm"), body language such as gestures made by the interviewee, and other relevant events were recorded. This information and other explanatory notes were enclosed in square brackets in the transcripts.

In the second stage of the study audiotaped, in-depth second interviews were conducted with eleven patients approximately nine months after the initial interviews. All of these interviews were conducted at the patient's home. The interview guide for this stage (included as appendix four) was developed to meet the aim of the second stage of the study, which was to explore any changes in the CR patients' perspectives on CHD and treatment. As such, the topics of interest for the interview guide were based on the topics and emerging themes from the initial interviews. These topics were formulated as: ongoing experiences of CHD; contact with health professionals and

ongoing access of health services or patient groups; perspectives on the risk of having another heart attack; and perspectives on treatment.

The topic on ongoing experiences of CHD covered what had happened to patients in relation to their health since the initial interview. This included how having CHD had continued to affect their lives and whether there had been changes since the initial interview. It was intended that this would lead in to the topic on patients' contact with health professionals and ongoing access of health services or patient groups. This topic included changes in their contact with health professionals (e.g. in frequency of use), whether patients had joined patient groups in relation to CHD and whether this had influenced their perspectives on CHD and treatment.

The topic on their perspectives on the risk of having another heart attack covered subsequent thinking about the cause of their heart attack, whether they were still as fearful about having another heart attack, how they thought about their risk of having another heart attack and the impact this had on their lives. The topic on their perspectives on treatment was mainly concerned with changes since the initial interview and whether this was connected to their perspectives on risk. The topic covered whether their medicines had changed, how they were coping with their medication regime, whether they took the medicines as prescribed and if not what the rationale for this choice was. Questions were included on whether they had maintained the lifestyle changes they had initially made, whether any new changes had been made since the initial interview, and the reasoning behind their choices. The guide was piloted in the first two interviews and as it was not found to need extra questions or prompts adding,

these interviews were not excluded from the sample. Unlike the interview guide used in the initial stage, changes were not made to the guide used during the second stage.

Technical problems occurred in the second interviews that caused problems with verbatim transcription. The pause button on the tape recorder slipped on in three interviews resulting in loss of recorded data, which was only a few minutes in two cases but in the other case resulted in the loss of approximately fifteen minutes of the interview. Detailed notes were made after the interview of what had been said in the unrecorded period. In another interview a fault with the tape caused the recording speed to increase such that roughly the latter half of the hour-long interview was inaudible on playback. Detailed notes were made of what had been said during this section of the interview and the interview was re-recorded onto another tape whilst adjusting the recording speed. This allowed the first fifteen minutes of this section of the recording to be sufficiently audible for accurate transcription. The other fifteen minutes mainly concerned the wind down at the end of the interview when little of significance was said. As such, the effect of this loss of recorded data on the construction of the data was considered to be minimal. All interviews were transcribed verbatim by the author.

In the third stage of the study audiotaped in-depth interviews were conducted with fourteen patients who had not had a heart attack (two patients were subsequently excluded as discussed in section 3.3.3). All of these interviews were conducted in the patient's home. The interview guide for this stage (included as appendix six) was developed to meet the aim of the third stage of the study, which was to explore their perspectives on CHD and treatment, so that these could be compared with the perspectives of the CR patients who had had a heart attack. As such, the topics of

interest for the interview guide were based on the topics used in the initial stage of the study and the second stage so that data could be generated about whether patients felt that their perspectives had changed over time. This meant that the data from both interviews conducted with the deviant case patient could be included in this sample for analysis of the data. As such, the topics of interest were formulated as: perspectives on CHD; perspectives on the risk of further CHD-related events; perspectives on treatment; sources of medicines information and education; and contact with health professionals and ongoing access of health services or patient groups. The issues covered in these topics were essentially the same as described above for the initial and second stages of the study.

The interview guide was piloted in the first two interviews and as no extra questions or prompts were found to be required, these interviews were not excluded from the sample. No changes were made to the guide in the course of conducting the interviews and no technical problems occurred, mainly because a digital recorder was used instead of a cassette recorder. These interviews were transcribed verbatim by an experienced transcriber but were meticulously checked for accuracy by the author.

3.3.5 Qualitative data analysis

Qualitative data analysis is a challenging process, which as discussed in section 3.2.5 is an integral and ongoing part of the whole research process, and not a separate activity that only occurs after data collection. It is an iterative, inductive process that involves considerable reflection on the data and the structure of analytical categories gradually evolves over time.

To start the analysis of the interview data, the transcripts were read and re-read over and over again to identify similarities between what the interviewees had said. Concepts embodied in these similarities were grouped into themes or categories and scrutinised in more detail to identify the properties or characteristics of each theme. According to the technique of constant comparison (as discussed in section 3.2.5), further interview transcripts were compared with the themes identified to examine the similarities and differences in detail. This resulted in the analytical categories being modified accordingly so that the properties of each category were more clearly defined or refined. Categories were compared with each other and relationships between them were identified and examined in detail in order to develop an overall structure. Care was taken to account for views or experiences that differed from the majority view, a process referred to in section 3.2.5 as deviant case analysis. By comparing deviant views with the majority view, the properties of themes were further refined and a clearer interpretation of the data was formulated. In one case this led to the third stage of the study, as discussed in section 3.3.1. The data and these developing analytical categories were discussed with the research supervisors.

Following training, the computer program QSR NVivo®, version 2.0.163 was used to aid the initial process of sifting through the transcripts. This involved highlighting passages of text that were examples of themes and cross-referencing these to similar passages from other transcripts to begin to develop the overall structure of themes. The program was found to be user-friendly and quicker and considerably more versatile to use than other analytical approaches, such as cutting up transcripts and pasting passages of text on larger pieces of paper, or using coloured highlighter pens to mark

passages of text. However, the use of computer software in no way detracts from the demanding mental processes required in analysis.

In addition to the notes made after each interview, as described in section 3.3.4, the author kept a journal of reflections and thoughts about interpretations of the data, which included diagrams of possible relationships between emerging categories to guide or reflect the analysis. This was found to be a highly useful way of recording thoughts that could be referred to later when reflecting on new data or new ideas. A considerable amount of time was spent thinking about the relationships between concepts in the data, the properties of themes and variations in the data. This in turn prompted further scrutiny of the transcripts and then further examination of the themes to ensure that the analysis was thoroughly grounded in the data and preconceived ideas were not being forced upon the data. This process continued throughout the study up to and including the stages of writing up, as further insights were gained (Charmaz 2006).

3.3.6 Confidentiality

In the interests of patient confidentiality, audiotapes and completed consent forms were kept in a locked cupboard to which only the author had access and only the author knew the identity of the patients. Similarly, interviews were conducted in a private location if not in the patient's home. Care has been taken to ensure that information has not been included in reports, publications or this thesis that might allow any patients, carers, healthcare professionals or hospitals to be identified. All of the participants were informed in the Patient Information Sheet that they read before giving their consent that these measures would be adhered to. These measures were adhered to because patient confidentiality was considered to be a key priority throughout the study.

3.4 Chapter summary

In this chapter it is pointed out that the choice of research methodology should depend entirely on the research question and a qualitative approach to this study was chosen on the basis of being better suited to exploring the range, depth and complexity than a quantitative approach. In-depth interviews were used because this technique enables individual respondent's perspectives to be explored in depth, although it is recognised that qualitative interviews are socially contingent interactions and the construction of the data is likely to be affected by a variety of factors, especially the identity of the researcher. The study drew on the broad principles of grounded theory as a practical approach so that the findings were grounded in the data. The overall aim of the study was to explore CR patients' perspectives on CHD and treatment using a qualitative approach. This involved an initial sampling stage, followed by two theoretical sampling stages to refine the emerging themes.

It has been argued that there is little agreement on how to achieve quality in qualitative research beyond the requirement that it should take a systematic, reflective and transparent approach to research design, methods of data collection, analysis, interpretation and communication. A reflexive approach to this was taken, which is why detailed discussion has been provided about the aims of the study, how participants were selected, how interviews were conducted and how data was recorded and analysed. Analysis of the data are now presented in the following four chapters, beginning with the initial stage interview data on CR patients' perspectives on having a heart attack.

Chapter Four

Patients' perspectives on having a heart

attack: analysis of initial interviews

4.1 Introduction

The aim of the initial stage of the study (as discussed in section 3.3.1) was to conduct in-depth qualitative interviews with a sample of CR patients after they had finished attending the CR programme (i.e. approximately three months after discharge from hospital) to explore their perspectives on CHD and treatment. For the purpose of analysis, as discussed in section 3.3.3, the patient who had not had a heart attack was excluded from the initial stage sample to leave fifteen CR patients who had had a heart attack. This aim of this chapter is to discuss the analysis of the data from the initial stage in-depth interviews that concerns these fifteen CR patients' perspectives on CHD.

Demographic information about the patients is included in section 4.2. Their descriptions of having a heart attack are discussed in section 4.3, section 4.4 concerns their explanations for why their heart attack happened and section 4.5 discusses their perspectives on the impact that their heart attack had on them. Key points are summarised in the final section of the chapter.

4.2 Patient demographics

Demographic information about the patients is summarised in table one. Patients' descriptions of their other medical conditions were used, as specific medical diagnoses

were not known in many cases. All of the patients were Caucasian. Thirteen patients were married and living with their partner, R12 and R14 were not living with a partner and none of the patients were related.

Table 1

Patient	Age	Sex	Occupation	Other Medical Conditions
R1	55	M	Manual worker	None reported
R2	72	F	Retired nurse	Degeneration of the spine, arthritis
R3	68	F	Retired playgroup leader	Diabetes, asthma
R4	42	M	Engineer	High blood pressure, high cholesterol
R5	61	M	Retired manual worker	None reported
R6	55	F	Podiatrist	None reported
R7	64	M	Retired bus driver	Spondylitis, high blood pressure, diabetes
R8	42	M	Civil servant	None reported
R9	60	M	Self-employed businessman	High blood pressure
R10	61	M	Retired office worker	High blood pressure, irritable bowel syndrome
R11	57	M	Teacher	Prostate problem
R12	54	F	Sheltered housing warden	None reported
R13	56	M	Civil servant	High blood pressure
R14	49	M	Manual worker	Indigestion
R15	60	M	Manual worker	Indigestion, heartburn

4.3 The experience of having a heart attack

At the beginning of the interview patients were asked what had happened to cause them to have to go into hospital. Despite having had their heart attack at least three months previously, all of the patients still seemed to have a very vivid recollection of events. With the exception of two patients, all gave detailed descriptions of what had happened before and during their heart attack without many further questions needing to be asked. This seemed to reflect how frightening the experience had been for them. R5's description was particularly detailed: He said that he had had his heart attack on Boxing Day and began by explaining what he and his family had planned to do that day. He then detailed the events that followed, which included placing a bet on a horse, watching the first race, going to his daughter's house, changing into his slippers and helping his grandson with a jigsaw before he started to feel unwell. His account of the onset of symptoms and the events leading up to him being admitted to hospital and receiving initial treatment was equally detailed.

The descriptions of having a heart attack that patients provided had a broadly similar format and, like R5's account, nine other patients began with a description of what they had been doing before they started to get symptoms. All of these patients talked about doing ordinary, everyday activities, rather than anything that they might have expected to cause a heart attack. For example, R6 had been "walking down the High Street", R7 had been in church and R8 said that he had "just gone down into the garden to clear up a few bits and bobs". This was explicitly stated by R15 when he said, "I wasn't hot, I wasn't flustered, I wasn't overworked or stressed and it just happened".

Patients then talked about how they had started to feel unwell, what their symptoms were and what they initially thought cause had been. After this, they talked about how the symptoms led them to seek medical care and the initial treatment they had received. Other prominent themes included realising how serious their situation was and their gratitude towards the health professionals who had looked after them. It was only after patients had described their experience of having a heart attack that they talked about other issues, which are discussed in sections 4.4, 4.5 and chapter five.

4.3.1 Interpreting the symptoms

Seven patients reported that their symptoms had got worse and worse over a period of several hours, whereas eight patients talked about feeling very unwell in less than an hour. Nine patients reported experiencing pain in their chest, which in five cases was accompanied by sweating, tingling in the arms and fingers, as well as nausea and vomiting. R4, R8, and R14 had felt clammy, nauseous and had started to sweat profusely before the pain started, whereas the pain started first for the other patients. R7, for example, described the pain as “like something ripping me insides out” and R14 said:

“Erm, well first of all I started to sweat violently you know. I had just been on a walk, come out of the shop and just started sweating and within what, ten minutes I had started feeling sick and started getting chest pains, tingling sensation in my arms.” (R14)

The other six patients reported experiencing chest tightness or chest discomfort rather than chest pain, which in two cases was accompanied by profuse sweating and nausea

and vomiting. R12, for example, said “it was like somebody squeezing all the air out” and R5 said:

“...they [ambulance crew] laid me down on their trolley like, two squirts of that stuff in the mouth like, hooked up the oxygen, they were asking me questions and I’ll never forget it, laid there trying to tell them what was happening to me and I couldn’t talk! The words wouldn’t come out... I had a tightness, my chest felt all tight and I was put into bed and I was wet through [from sweating]. My body was like I’d just stepped out the bath! I was totally drenched, I couldn’t believe it. It frightened me, it really did.”
(R5)

In addition, R4, R7 and R11 “passed out” or “blacked out”. R11 in particular described how he had collapsed on his drive and then had to be resuscitated in the ambulance:

“I was just walking out the house and I collapsed. Yes I totally blacked out. So I bashed my head, my elbow, my hip and the next thing I can remember is lying on my back by door out there in a puddle of water as it had been raining and wife looking down at me as she was close behind me but she didn’t stop me falling... I remember going in the ambulance they got me a wheel chair thing or trolley and took me into the ambulance, and I was sick actually, I was violently sick in here and in the ambulance. Anyway in the ambulance I can’t remember this but my heart stopped. They had to get the old paddles out, the wife knows more about this than me and they started my heart.” (R11)

Only R14 said that he "knew" his symptoms of chest pain that radiated down his arm, nausea and sweating were cardiac in origin because other people in his family had had heart attacks and had experienced similar symptoms. None of the other patients initially realised that they were having a heart attack and had attributed their symptoms to other causes. R12 said that she had not thought she was having a heart attack because she was not in pain:

"I always thought heart attack you would be screaming in pain and falling down but you don't." (R12)

Six patients thought that they had indigestion, whilst other perceived causes included a pulled muscle (R1), asthma attack (R3), chest infection (R13) and R2 (a retired nurse) thought she might have got cholecystitis or pancreatitis. Three patients did not indicate what they thought had caused their symptoms. The following quotes are examples of how patients initially interpreted their symptoms:

"We were on the way to take our daughter and son in law to Manchester airport and I said, you know, it'll go off it's just an asthma attack but it didn't, it got worse and worse. So by the time we got to [nearby town] it was a case of come on you can't go on like this Mum, we must find somewhere for Mum to go and so I finished up at [nearby town] hospital."
(R3)

"I felt poorly, but put it down to a bit of a hangover even though we didn't go out on New Years Eve. Just thought, oh it was one of them things and

I'm the sort of person who's always had a bit of a gippy tummy. But as the day went on I felt more and more poorly and was being sick fairly regular... You know I honestly thought it was indigestion of some, or I'd pulled myself with beer, I was so sick.” (R4)

Only three patients reported that they had attempted to treat the symptoms themselves. R1 had taken paracetamol, R2 had taken, “a couple of aspirin...just in case it's anything sinister” and R6 had tried a variety of measures to no effect:

“I tried indigestion relief with no effect, the Remegel chewable things. I then tried a Nitrolingual [GTN] spray that had prescribed about nine months earlier when he [GP] suspected angina. I'd never used the spray before, it was the first time I'd used it. No effect from that either, had a warm bath, which solves most of my problems but didn't solve this one! I was very sick, went to bed, dozed off in a more or less upright position, woke up about twenty minutes later and the pain had not eased.” (R6)

4.3.2 Seeking medical care

The severity of their symptoms seemed to have prompted patients to seek help or advice, although only R2 and R14 directly sought medical care themselves; R14 recognised that he was having a heart attack and phoned for an ambulance, whilst R2 “knew it was serious” and phoned NHS Direct, who advised her to go to hospital. All of the other patients told their partner or a work colleague about their symptoms and it was the partner or colleague rather than the patients themselves who advised seeking medical care and initiated the process of doing so. This happened by either phoning for

an ambulance, phoning the patient's GP, insisting that the patient go to see their GP or taking the patient to an Accident and Emergency department (A&E).

In five cases the patient's partner (or in two cases a work colleague) phoned for an ambulance. R11 said that when he told his wife about his symptoms she had said "I think we should get you to the doctor's surgery" but he collapsed as they were leaving the house to go. R10 said that he had intended to see his GP but when he vomited and his chest pain became severe his wife realised that his condition was serious. R12 said that her manager "took one look" at her and phoned an ambulance, whilst R15 spoke to a first aid trained colleague at work who "wasn't taking any chances" with him. R5 was aware that he was ill because he was sweating profusely had chest tightness and had vomited twice but said that when his wife saw him she had "twigged" how serious his condition was and phoned an ambulance:

"You see I think she had an idea what had happened because all the colour had drained out of me." (R5)

In five cases the patient's partner phoned the GP for advice (or NHS Direct in one case) and in three of these cases an ambulance was sent. For example:

"And in the end I had to send my daughter over to get my wife because she was at work and they came back and phoned the doctor and he said oh we'll just phone an ambulance, basically he's having a heart attack."
(R8)

In the other two cases the partner was advised to phone for an ambulance if the patient's symptoms got worse, which they subsequently did. R1 said that his wife had made the decision to phone the GP because he was "not one who wants to waste anyone's time". Both he and his wife had thought it was a "bad case of bronchitis" and he pointed out that he had "to be genuinely in real pain before I go to see a doctor", so the GP advised his wife to phone for an ambulance if his pain became worse. It was only when his pain became considerably worse that she phoned for an ambulance:

"And the wife called the doctor and 'cos I'm such an awkward person I wouldn't. And the doctor said she wanted to get me in [to hospital] and I said, no I'm not going. I said, I'll make do with the painkillers. So ten minutes after she went I got another pain and the wife phoned for the ambulance." (R1)

R9 said that he had had chest pains during the night and his wife had "insisted" that he went to see the GP, who told him to go to A&E "and make sure the wife drives you there". As shown in the quote in section 4.3.1 above, R3 thought she was having an asthma attack and her family who were with her in the car persuaded her that she needed to go A&E. R7 said that he had started to have chest pains whilst in church so his wife took him to A&E but he had collapsed in the hospital car park:

"Last thing I remember is getting into the car park and them whipping me out on a stretcher and getting me into casualty" (R7)

4.3.3 Realising the seriousness of the situation

A key theme in patients' descriptions of having a heart attack was how and when they had realised the seriousness of their condition. In this regard, a particularly striking feature of six patients' descriptions (R2, R4, R5, R10, R13 and R15) was how traumatic and frightening the experience of having a heart attack had been for them. These six patients were also the ones who gave the longest and most detailed descriptions of what had happened before and during their heart attack. For example, R10 said that he had been "shocked" by how severe the pain became and R5 in particular said, "it frightened me, it really did" (as shown in the quote in section 4.3.1 above) and added "I've never been so scared and I've had active service in the forces". Their experience appeared to have been traumatic and frightening, partly because the intensity of the symptoms had been distressing but also because they thought that they might die, even though they did not realise that they were having a heart attack at the time. When told that they were having a heart attack and needed thrombolysis (or a "clotbuster", as they put it) this confirmed that their condition was indeed serious and two patients (R4 and R10) described themselves as being lucky for having survived the heart attack.

Of the other nine patients, R14 recognised that he was having a heart attack and was aware that it was a serious situation, which is why he had phoned for an ambulance. Four patients only started to realise how serious their condition was when they were told that they had had a heart attack and the other four patients started to realise when they were told that they were having a heart attack and needed a "clotbuster". For example, when the risks of thrombolysis were explained to R2 she had readily given her consent because, "you're so ill you've got to take any risk" and R10 said that when he was told that he was having a heart attack:

“It hit me that that’s what it was then. I suppose, you know, the worry sets in doesn’t it...there’s all these thoughts going through your mind that, you know, is this the end? Am I going to come through it at the other end, you know?” (R10)

As such, the only initial treatment that appeared to stand out in nine patients’ memories was having a “clotbuster”, as this was seen as an important treatment that would specifically deal with the cause of their symptoms. For example, R2 described it as “the drugs that are going to save your life”, four patients said that they had felt quite well soon after thrombolysis and R10 said that the thrombolytic:

“...would dissolve this clot that was causing the blockage and causing the pain, causing the difficulty.” (R10)

Patients did mention one, sometimes two other treatments they had received but these were mentioned after they said about having the “clotbuster”. For example, R2 and R6 said that they had been given oxygen, R4 and R14 said they had been given “something to take the pain away” and R6 remembered that she had been given aspirin. Of the six patients who did not say that they had been given a “clotbuster”, two patients said they had been given oxygen, one patient said he had been given a painkiller, two patients said they had been put on a “drip” and two patients said they had been “wired up” to a heart monitor. In general, patients said much less about their treatment in hospital than they did about the events that led to them being in hospital and thirteen patients conveyed their sense of bewilderment at all the activity going on around them during their initial treatment. The following quotes are examples of this:

"You don't see anything except trolleys and wires and get various needles put in and oxygen." (R2)

"There's needles and things stuck in my arm and I've got a mask on my face." (R9)

As a result of recognising the seriousness of their situation, three patients talked about re-evaluating symptoms of "indigestion" they had experienced on other occasions. R6 talked about an incident the previous year where she had had chest pain that she had thought was "severe indigestion" but was now "ninety-nine percent certain that I'd had a heart attack ten months earlier". R14 had had a lot of "indigestion" prior to his heart attack and wondered whether this had been angina, especially as his brother had also had a lot of "indigestion" before he had died of a heart attack two weeks after R14 had his heart attack. Similarly, R2 said:

"It was a really, really bad week with all this indigestion, it must have been angina, in retrospect." (R2)

Realising the seriousness of their situation also involved the recognition that they really had *needed* medical care. Associated with this was the considerable gratitude that all of the patients expressed towards the health professionals who had looked after them, especially the ambulance crews, A&E staff and Coronary Care Unit (CCU) staff who had looked after them when they had been most ill. R7 also expressed his appreciation that his GP had unexpectedly visited him at home to "make sure everything is alright".

4.4 Explaining the cause of the heart attack

4.4.1 Lifestyle and non-lifestyle causes of the heart attack

All of the patients expressed a sense of shock that they had had a heart attack, which could be seen in their descriptions of having it. Nine patients explicitly said that it had been a shock. Eleven patients talked about why they thought they had had a heart attack and it seemed that this was an important issue for them, mainly because of the implications for preventing further heart attacks. In contrast, R3, R5, R7 and R9 did not talk about possible causes.

A variety of lifestyle factors were cited as possible causes of their heart attack, which included smoking, job-related stress, being overweight, diet and lack of exercise. The most commonly cited factors were smoking (five patients) and job-related stress (five patients). R1 referred to smoking as a possible cause when he said, "it's not done me any favours". R2 said, "it was a contributory factor that I smoked and I'm overweight". R10 also referred to smoking as a possible cause when he said, "so that was the only thing I can put it down to". R12 said that the doctors had told her that smoking was "the reason why it could have happened", although she said that job-related stress had also been a cause. R14 talked about smoking and diet being causes, R6 talked about job-related stress and having "a very sedentary job, sitting around all the time". R4 referred to having hypercholesterolaemia and a "fairly stressful job", although he talked about stress as a cause of his hypertension rather than his heart attack. R8 talked about having "a lifestyle where I would work very long hours, stressful job" and that when he came home "it was telly and fast food". R11 also talked about having a "very stressful job" as a possible causative factor and that his "diet was too high in cholesterol". R15

talked about job-related stress, lack of exercise and heavy coffee consumption as possible causative factors.

The non-lifestyle causative factors cited by the patients included stress (unrelated to lifestyle) and heredity: R14 said, “for the last five years or so I have had no end of stress”, as a result of having previously had cancer, and cited this and heredity as causes of his heart attack. Heredity was also cited by R11 and R13 as a cause of their heart attacks. R14, for example, commented on how many heart attacks his various relatives had suffered:

“My grandfather he had quite a few heart attacks. It seems to be in the family at the moment, in the male side. My uncle on my mother’s side he suffers with his heart, my brother died of the heart attack, I’ve had a heart attack like and you know. It seems to be the sort of thing at the moment.”

(R14)

In providing their explanations for why they thought their heart attack had happened, none of the patients indicated that they thought they were to blame for it, although only R5 explicitly talked about this. He said that when the paramedics were putting him in the ambulance he had seen how concerned his family were and “thought what the bloody hell have I done here” but added “although it were no fault of mine like”.

Three patients seemed to be reasonably certain about the causes of their heart attack. Of these, R8 explained his heart attack as being a combination of “fast food”, diet, lack of exercise and job-related stress. R14 talked about his family history of heart attacks

(as shown in the quote in this section above), stress as a result of having previously had cancer, smoking and diet as causes. R11 considered that his heart attack was caused by the culmination of heredity, job-related stress and having a diet “too high in cholesterol”:

“I mean I’m fairly fit, I do a lot of road running, I’m not overweight, I don’t smoke, I don’t drink much alcohol. The only two things that count against me probably was the fact that it runs in the family, my father has also got problems and my brother having a triple bypass and the fact that really my diet was too high in cholesterol and I had fairly higher than normal cholesterol level and major stress as well. So you know I had some inherent factors and the stress factor and the cholesterol.” (R11)

4.4.2 Uncertainty about the cause of the heart attack

The other eight patients appeared to be uncertain about why they had had their heart attack. R1 expressed this when he said, “nobody has sat me down and told me why it’s happened”, even though he acknowledged that smoking had not done him “any favours” and that he had been told to lose weight. R15 also seemed uncertain about the cause because nobody had been able to tell him why it had happened, since it was a “combination of so many things”:

“Of course I asked the question what do you think brings the heart attack on and I suppose nobody can actually say; it’s a combination of so many things. I happen to think that stress is one of the factors and maybe lack of exercise and perhaps if I’m being honest too much caffeine in coffee, I

tended to be rather a heavy coffee drinker in the morning...I don't smoke, I do like a beer, I don't drink heavily and I don't believe I am grossly overweight. Maybe, looking back, I didn't exercise and maybe I've got to exercise and maybe if I think about it, to be honest perhaps I occasionally over-ate and left the table feeling too full." (R15)

He explained that his job-related stress related to the difficulties he had had with the introduction of new working practices, such as having to learn to use a computer, as a result of the company he worked for being taken over. He also said that he found it difficult working as hard as his much younger colleagues. R4 could not find any obvious lifestyle causes to explain why he had had a heart attack. He had been diagnosed two years previously with hypertension (which he thought may have been a result of job-related stress) and hypercholesterolaemia, but questioned whether these could have been causative factors largely because he was taking medication to "control" these conditions. He talked about friends who had altered their lifestyles and had their cholesterol level and blood pressure checked because they had been shocked that he had had a heart attack. Nevertheless, as the following quote shows, he was left with a strong feeling of uncertainty as to how much these factors, if indeed either of them, had been responsible for his heart attack:

"Trouble is, in a lot of ways, you know, I was forty-two when I had the heart attack and everyone is saying to me, yes you're quite young, do you smoke? No. Do you drink heavily? No. Do you not exercise? I do exercise. Are you overweight? No, you know, so, and I'm thinking I don't know, why the hell have I had a heart attack...None of the criteria that they say; didn't

quite fit, I don't know. I had a fairly stressful job but, you know, I was already on the tablets for high blood pressure and I'd got fairly high cholesterol, not mega high cholesterol and I was on the tablets to control it. I had the cholesterol checked the Monday before the heart attack and when I did manage to get the test results I think it was, er six point three, something like that. So it was over the five but still, you know, there's a lot of people walking about with far higher cholesterol. Yes, so you have a lot of questions like that as to why it should happen really." (R4)

Similarly, R13 seemed to discount his hypertension as being a causative factor because it was "being treated" and pointed out that he had thought it "strange" that the doctors had been "concerned about my cholesterol, which is not high". He said that he had come to the "conclusion" that heredity may have been responsible because his father had had a heart attack, although his comments suggested a degree of uncertainty about this:

"Everybody was saying in the hospital out of all the risk factors I was at the bottom ten percent, I suppose that's very useful to know but I've had a heart attack! I've come to the conclusion knowing all this; if it's your family then you have got a question before you start, that's the difficult one. They can treat everything else but if it's hereditary? That's very difficult to spot and pick up on and deal with." (R13)

R10 said that several years ago he had been diagnosed with hypertension that "within a very short time was picked up, diagnosed and controlled, you know". He went through

all the lifestyle factors that did not apply to him before saying that “all I’m left with is smoking”, which suggested that he was uncertain about this explanation for his heart attack.

Three patients (R2, R6 and R12) drew on their ideas about the sort of person who is likely to have a heart attack in their explanations about the cause, which suggested uncertainty. R12 said that her “cholesterol levels weren’t high” and that she had “never had high blood pressure”, so had considered that the “only reasons” were smoking (because the doctors had told her so) and job-related stress. She explained that “the year before I had quite a lot of stress with a woman I had worked with before and things got quite hard to work together” but then she had changed job “so I don’t have contact with this woman and things were going swimmingly and all of a sudden [she had a heart attack], so I don’t know whether I was beginning to relax again”. Her uncertainty about stress being a cause seemed to be shown when she said, “I don’t really think I get stressed, not really, but maybe I do and don’t realise it”. She added that, “it seemed so out of character for something like that to happen to me”, which was because the sort of person she thought would have a heart attack was someone like her mother:

“Someone with high blood pressure, someone who always gets worked up and stressed, someone like my mother. We always say you will have a heart attack or a stroke if you’re not careful because she is always stressed and has high blood pressure and everything and I don’t.” (R12)

R6 said about experiencing the symptoms, “I guess I was in denial because I thought that someone like me wouldn’t have a heart attack”. She explained that she had “never

had a weight problem”, “diet has never been a problem because I always enjoy what happens to be good for me” and that blood tests had “suggested I’ve not had a cholesterol problem either”. As such, she said, “the only reasons I could come up with for my satisfaction were probably lack of exercise and stress” but pointed out that “no-one has ever said really why it happened but then, you know, the answer’s not always clear is it”. To emphasise this point she talked about her manager’s recent death from a “massive heart attack”. She described him as “only forty-nine, super fit, he used to run round the block every day” and noted that he had no family history of CHD, before suggesting that he “possibly overdid it” because his “exercise routine was not the best for him”. R2 said that smoking and being overweight had been *contributory* factors (i.e. not the only reasons) but explained that due to other problems with her health she had been unable to exercise:

“...It was also a contributory factor that I smoked and I’m overweight, but I do have a back problem. I’ve got a degeneration of the spine and arthritic knees. The point about this is that if you’ve got anything like that you can’t walk anyway.” (R2)

She said that she had had a cholesterol test two years previously, which had shown that her cholesterol level was “slightly raised” but no medication had been prescribed for it. She added that it made her wonder “how I would have been if I’d had something then”. Her uncertainty about the cause of her heart attack seemed to be further shown when she talked about a conversation she had had with R6 at CR, who she did not think had had these “contributory factors”. She described her as “fit, she didn’t smoke, wasn’t overweight”, said that she was only fifty-two, slim and that she had “said she did

do exercise and things like that”, before saying “you know, you can be doing all the right things, can’t you”.

4.5 The impact of having a heart attack

It was clear that having a heart attack had had a profound impact on the patients and had affected them and their families in many ways. Four main themes emerged from what patients said about how their heart attack had affected them, which are termed: fear of having another heart attack; feeling tired and wiped out; wanting to get back to normal; and trying to take all the information in.

The amount that patients said about the impact that their heart attack had had on them seemed to be principally related to how much they continued to be affected by it in their everyday lives: R1, R4, R7 and R15 seemed to be more anxious than the other patients and talked a lot about the difficulty and uncertainty in their lives. In particular, R1 said, “I’m not sleeping much, I think since my heart attack I’ve only had one nights sleep...the doctor seems to put it down to anxiety, worrying about the heart attack”. His anxiety is particularly shown in the following quote:

“All the hospital said was relax, don’t worry, you know don’t overdo it, take it easy. You can’t go still; you’re sitting there some afternoons and you can’t help but sit there and worry about things. You can’t just sit there and switch your mind off and think this never happened. People say don’t worry, its easy to say don’t worry it’ll be alright, but until it’s actually happened to yourself and you’re sitting there in the afternoon. I’ll tell you, sometimes I’m sitting in there in the afternoon and it’s easier to sit and

stare at the bloody wall! And it's don't worry, everything will be alright but in the back of your mind you worry all the time about it." (R1)

Talking about his problems and fears in the interview seemed to have been cathartic for him, as towards the end he said, "I think I've got everything off my chest". R2 seemed to have more physical difficulties than the other patients and talked a lot about how being breathless and easily exhausted affected her. Three other patients continued to be affected by having a heart attack, which was evident from what they said, although they did not talk at length about it. R9 talked about being depressed, whilst R5 and R10 seemed anxious and fearful of having another heart attack. R5 was also frustrated by having not returned to his previous level of physical functioning.

In contrast, the other seven patients said much less about how much they had been affected but most had no ongoing physical symptoms except tiredness, which had only really been a particular problem in the first few weeks after discharge from hospital. Five of the six patients who had not retired had gone back to work and R11 was planning to retire from his stressful job and do something else. As such, the ongoing effect on their everyday lives seemed to be less than the patients who were especially anxious. In particular, R6 expressed a sense of guilt about being off work because she did not feel ill and said, "I'm the sort of person who feels guilty about having time off on full pay, particularly if I feel alright".

4.5.1 Fear of having another heart attack

Eleven patients talked about being worried that they might have another heart attack, especially that it might be fatal. This was expressed in three ways: a generalised fear of

“what if it happens again”; the fear that symptoms meant that “it is happening again”; and the fear they might “do something to make it happen again”. In contrast, R11 talked about not being worried about having another heart attack, mainly because he had decided to retire from his “stressful” job, since as one of his colleagues had pointed out, “health is better than wealth”. R3, R6 and R9 did not talk about fear, although this did not necessarily mean that they were not worried about having another heart attack.

Seven patients (R1, R2, R4, R8, R10, R14 and R15) seemed to express their fear in terms of “what if it happens again” and used language and tone of voice to convey the feeling that if they did have another heart attack it could happen suddenly and be catastrophic, if not fatal. R10 said, “you have this idea in the back of your mind that you might suddenly go”, whilst R2 and R8 talked about being worried in case “anything happens”. R1 was particularly anxious about whether he would be able to go back to work and implied that his company now saw him as a liability:

“Whether my company will have me back ‘cos it’s a physical, manual job and being a small company they don’t want me down the other end of the yard now I’ve had a heart attack. If I’m down the other end of the yard on my own for a couple of hours, nobody is going to miss me. What happens if it happens when I’m down there? I can see their point of view but at the same time I’ve got to look at my own point and I need wages coming in.”

(R1)

R15 said, “the last thing I want is to come back [to hospital] again because the next one might be more debilitating than the last one”. R14’s brother had died of a heart attack

two weeks after he had his heart attack, which had heightened his fear and R4 said that he felt anxious whenever he went anywhere in case he was too far away from an A&E unit and needed urgent medical care:

“I still feel anxious going anywhere, really, anywhere out of the town. I’m sure that was the case when I went to [large city] that, you know, felt myself getting further and further away and even looking out on road signs for where the nearest A&E is [laughs].” (R4)

Four patients (R4, R5, R7 and R12) talked about how experiencing angina or breathlessness made them fear that they might be having another heart attack. R7 had had frequent angina since his heart attack and after an angiogram had been told that he had a partially occluded coronary artery, or as he put it an “artery that’s going”. This made him worry even more when he got angina that “here we go again, this time it’s the one”. R4 also experienced chest pain, or “discomfort” as he put it, that added to his fear of having another heart attack, particularly that the doctors and the CR nurses were not sure whether it was angina and tests were still being done to find out. R12 said that she had particularly worried about getting “twinges” of chest pain or discomfort in the first few weeks after discharge from hospital:

“Well you worry don’t you, quite a bit when you first come home; can I do this, can I do that. Every little twinge and you think oh my God...Yeah you think oh God what if it happens again.” (R12)

R5 talked about being scared that he was having another heart attack when he had been out in a cold wind and had found it difficult to breathe, which had heightened his fear of having another heart attack:

“It’s there the whole time in that some time later there’s still the possibility that it could happen again...I went out Saturday morning for a bet and I thought I’ll go the long way round and I was six hundred yards from the sea, off our road, round the corner across and up hill. And that cold wind were hitting me and I’d no alternative then but to not go on seafront but to go around and I was fighting for my breath! That cold wind hitting me! It was halfway across my mind, yes I were panicking because it were cold wind. You see it’s them sort of things that puts it in the back of your mind that it’s going to happen again to me.” (R5)

Three patients (R10, R12 and R13) talked about being scared of “overdoing it” or doing anything that might cause them to have another heart attack, even though they had not been doing anything of this nature when they had had their heart attack. R12 said, “you worry don’t you, quite a bit when you first come home; can I do this, can I do that” (as shown in the quote above), R13 said that he had “been anxious to know how far you could actually push yourself without supervision” and R10 said:

“I suppose it was a fear in the back of your mind that you were frightened of doing something that’ll bring it on again. So sort of things like the basket of logs there, well I didn’t even attempt to carry that, I got a little cardboard box and put two or three logs in and brought them in, so you know did ten

trips instead of doing one big basketful. The coal bucket I only half filled instead of filling it to the top. And then I had some odd bits and pieces I wanted to plant in the garden and one of them was a bush and a big rhubarb and I thought well, I don't know whether I dare dig the big hole, when I say a big hole it wasn't big; it would have been the size of this seat. But you don't test it; you don't know whether you should, whether you would be overdoing it or what." (R10)

This had been a particular fear in the first few weeks after discharge for all three, although R13 and R12 had been reassured by attending the CR programme that they could exert themselves without having another heart attack. On the other hand, R10 talked about having become less fearful by "realising just how physical you can get without having, you know bringing another attack on" but still worried that he might "overdo it". He explained that he had started filling the coal bucket again and carrying the log basket, although still only half full.

Four patients (R1, R2, R10 and R15) also talked about how much they had valued a home visit from the community CR nurse (CCRN) during the first few weeks after discharge from hospital because it had given them the opportunity to talk about their fears and problems on a one-to-one basis. For example, this had helped R10 to realise that he could carry things without having another heart attack, and R2 and R15 said:

"I think it's when you go home you feel alone. That's where the Coronary nurse comes in [CCRN] because it's a bit scary when you're at home on

your own. What do I do if anything happens, sort of thing... he was very good.” (R2)

“The nurse [CCRN], the lass that lives in [local town] that came to my house and she spent an hour and three quarters with me on a one-to-one. I mean I really valued that. That was a great help to me. She answered all my questions. She seemed to know instinctively what my problems were but then she is trained to do that isn’t she.” (R15)

R1 said that the CCRN had “got that bit more time to sit and talk to you or to advise you” and that “we had a chat and that”, which he had appreciated because he felt that he did not get enough time to discuss his problems with his GP:

“I’ve always been under the impression with my doctor that he’s got another patient to see. You get this with the doctor. I had this not last time but the time before with my doctor. I went to see him to tell him how I was feeling, the cough and not sleeping, breathlessness and we got the distinct impression that he just wanted me out the door.” (R1)

On the other hand he had felt that the CCRN had not given him any information on his “specific case” because he was “only talking general” and had not got his “[medical] notes or anything”. This seemed to relate to his uncertainty about why his heart attack had happened, whether his heart had been damaged and his fear of having another heart attack. As such, he felt that his GP would have been the “ideal” person to talk to:

“The ideal person should be your doctor. They’ve got all your medical notes and it’s all on screen. Someone you can sit down and talk to. I’m not saying sit down and talk to him for twenty-four hours. I just want to sit down and have enough time to have a decent conversation to get everything off your chest, how you’re feeling and he can tell you what’s happened or what is going to happen or anything because they’ve got more idea than I’ve got.” (R1)

4.5.2 Feeling tired and “wiped out”

Seven patients talked about either feeling tired all of the time or soon becoming exhausted (or “wiped out”, as one patient put it) when trying to do things, which had been a particular problem in the first few weeks after discharge from hospital. Four patients (R6, R10, R11 and R15) talked about feeling tired all of the time. R15 explained that he was finding it difficult being back at work, even part-time, because he felt so tired as well as that he now got angina. As a result he seemed to be quite concerned as to whether he would be able to continue working and work colleagues’ suggestions that he was not doing his fair share of the work added to his anxiety. R11 said, “I tend to be a lot more tired” and recounted how one afternoon “after about two o’clock I was sitting there doing the crossword out of the paper and I’ve gone off to sleep, [laughs] I’ve fallen asleep”. R6 talked about “being half asleep” all of the time and R10 said:

“I don’t know what it was but I felt tired and I didn’t have the energy or the appetite I’ve got now” (R10)

Three patients (R2, R3 and R7) found that they soon became exhausted when trying to do things. R3 talked about being “unable to do all the work in the house” when she was first discharged from hospital because she soon felt tired, even though she “felt a new woman” because her breathing and mobility had improved. R2 said that she had felt “wiped out” and breathless throughout her time in hospital. She said that having a heart attack “knocks the stuffing out of you” and “when I came out of hospital I was as weak as a kitten; I couldn’t do anything”. She added, “I haven’t been able to do anything since I came out of hospital” because even small jobs left her feeling “totally wiped out”. R7 talked about becoming easily tired when trying to do jobs in the garden and how frustrating he found this:

“I don’t do anything I used to do...I used to do a lot of things, potter about the garden, in the shed, things like that but I don’t now because I get livid...Trouble is you look at the job and you think that’s an easy job that, and by the time you’ve finished it it’s been a major job” (R7)

4.5.3 Wanting to get back to normal

Eight patients talked about their desire to get back to their previous level of functioning or “wanting to get back to normal”, as three patients said. This was expressed in two ways, either frustration at not being able to do things they previously could do or determination to recover. Five patients (R1, R4, R5, R7 and R9) expressed a sense of frustration at not being able to do things they had been able to do prior to their heart attack. R5 said:

“To be honest I’m still trying to get my head round it! I mean I still can not get my head round that I have had a heart attack and I want to be doing the things what I were doing last year”. (R5)

R4 was frustrated at not being able to go back to work and wanted to “get back to a little bit more of a norm”. He had asked his GP several times when he would be able to go back to work and each time had been told, “we’ll give it a couple more weeks”. He said:

“I’m fed up and I’ve been pretty fed up all the way through, a little bit angry, not knowing why I’ve had a heart attack and just wanting to get back to normal.” (R4)

R7 felt that his life had been affected in a lot of ways and gave a number of examples of how he had been restricted from doing things. This included gardening, as discussed in section 4.5.2 but went further:

“Well it’s affected me personal like because I’ve had to stop swimming, I was learning to swim. They won’t let me go in the pool now because of the temperature. Even the one I was going to, that water is freezing when you first get into it. It’s that first shock to the system and they think it’ll be too much of a shock to the arteries and that. Plus I can’t play with the grandchildren like I used to, you know, I have to be very careful of it.” (R7)

R1 felt that “everything is happening...it’s been one thing after another and there doesn’t seem to be any sort of end to it”, since after his heart attack he had been

diagnosed as being diabetic, hypertensive, hypercholesterolaemic and had then also had chicken pox. He had been referred to the dietitian, started on warfarin, which required regular blood tests to optimise dosing, and had had various investigations such as exercise tolerance testing done as an Outpatient. This had left him feeling frustrated at not being able to go back to work sooner:

"I've never been to so many doctors in a hospital or that many times in all my life as I have the last two or three months. Tuesday was the only day this week when I hadn't had to go to hospital...Next week I've got up here [Outpatient clinic] Monday blood clinic, Wednesday at the [Community hospital], Thursday I'm up there again to see their dietitian and they said you can go back to work, but you have time off to see all these doctors and you can't go back to work!" (R1)

R9 said that he was not "back to where to he was as far as doing things", mainly because a few weeks after being discharged from hospital he had started to feel quite depressed:

"I have got a bit of a, well they tell me it's a bit of a mental problem at the moment, you know depression problem. I've got a history of a bit of depression anyway and when I left [hospital], two weeks after my heart attack I was ready to take on the world but now I'm crap. You know, went to see the GP, talked to him about it, wife carted me off to see a psychiatrist and yeah, I feel better by talking about it, so it's some way

towards it...Yes, I feel I've got round the heart side, it's the bloody head side now! ” (R9)

Three of these patients said that their activities had also been restricted by family members, who were concerned that strenuous activity would cause another heart attack. This was presented as adding to their frustration. R4 said, “wife’s overprotective; can’t help that can you and I think that’s a natural thing”. R7 said, “I don’t do anything I used to do, actually think it’s because the wife and son won’t let me” and R5 said:

“Every time I try to do it [gardening] I get bellowed at! [Laughs]. It’s not that she [wife] means bad when it’s the right thing like. I suppose it’s me being a bit awkward. It’s just me wanting to be back to normal and I’m not normal anymore, sort of thing, in one respect.” (R5)

Rather than being frustrated at not being able to do things they had previously been able to do, three patients expressed their desire to get back to their previous level of functioning by talking about their determination to recover. R15 talked about having to “build yourself back up again”, which he seemed to view as a responsibility to his family as much as to himself, or as he put it, “I owe it to them”. R12 said, “you have to be normal and just carry on again and just be a bit more careful in what I do do”. R2 said, “it does worry you that you’re breathless, can only walk so far and you’re puffing away”. She added, “my husband has been taking me out to the supermarket and things like that” because “you’re not physically well enough to go anywhere; you’re too exhausted”. Despite this, she viewed getting “better” as a matter of willpower:

"I don't see why life shouldn't be the same. You can't make yourself into an invalid, that's what you shouldn't do. I mean the same within reason, I've got to get better and the way I see it each day, each week I'm better than I was. I know it takes longer because I'm older; some of the younger ones will probably pick up quicker than I will. I do think willpower has a lot to do with it." (R2)

Of these three patients, R12 talked about her son being overprotective. She presented this in terms of how frightened he had been and that he was realising that she could do things without having another heart attack, as she was finding out herself. This demonstrated how "you have to be normal and just carry on again", rather than being frustrated.

"My son's at home as well and he was oh don't do this, oh you can't do that...so it really frightened him. It was every time I was going to do it, no you're not allowed to do this and it was hell to start with but as time went on it got a bit easier for him." (R12)

R15 did not feel that his wife had been overprotective, rather he talked about how supportive she had been:

"Every day she [wife] says to me you are doing well and you're looking good and you are sounding positive, don't get in a flap...Be calm. Don't let anyone push you around. She gives me these little pep talks and that's helpful. She has been very supportive without nagging" (R15)

4.5.4 Trying to take all the information in

Thirteen patients talked about the doctors explaining what had happened and answering any questions they had had whilst they were in hospital (this was implied by R3 and R14 but not actually said). In addition, all of the patients talked about being given written information about CHD and treatment by the CR nurses and other health professionals. All of the patients expressed that they had valued this information, although R6 said that initially she had not been told that she would be staying in hospital for several days. Subsequently, she had assumed that she would be going home the next day because she felt so much better after thrombolysis. R1 appreciated being given information but felt that most of it had been too general and not specific enough to him, as discussed in section 4.5.1.

Of these thirteen patients, seven talked about their difficulty in trying to take all of this information in, especially in the first three days after their heart attack when much of it was given. R2 said, “you are a bit vacant at the time, you don’t take it in the first time they come to see you at all”. R9 said, “especially in the first instance that your doctor tells you something, there’s only about fifty percent of it stops with you” and R10 said, “when I came out [of hospital] I’d forgotten half of it”. R14 said, “it’s just too much to take in”, R12 expressed this feeling when she said, “there’s so much literature about at the hospital that they just give you it all” and R8 said:

“I think a lot of the information kind of comes in a stage when you’re, you’ve had the heart attack and you’re still trying to take in all that’s going on really I guess. And I think just, you know you come in and you’re at the emergency then you’re on the assessment ward and the next day you’re

you find out you're staying in and you're on to another ward and it's often in that context that people are giving, you know pharmacists and nurses and people, are giving you information so some goes in and some you just can't take it on board at that time.” (R8)

R13 said that on the first day after his heart attack he was “out of it” but once this feeling wore off he was then able to take the information in and had been keen to “read every leaflet that there is”. He generally felt that he had been told what had happened with “no pussyfooting around” but talked about health professionals using jargon that he did not understand. As an example of this he talked about the Consultant asking how his angina was, which he didn't realise at the time meant chest pain:

“I was asked by [Consultant] how was your angina? Well, what the hell is angina when you've never had it before? [Laughs] Well it's the chest pains that are angina. Well I didn't know, but I now know that any chest pains you have from now on are angina.” (R13)

4.6 Chapter Summary

All except two patients gave detailed descriptions of what had happened before and during their heart attack, which indicated that it had been a frightening experience for them. Patients typically explained that they had not been doing anything unusual before their symptoms started, pointed out that they did not initially recognise their symptoms, explained that their partner or colleague had initiated or advised seeking medical care, and described the initial treatment they had received. Patients also talked about only

realising how serious their situation was when told they were having a heart attack and their gratitude towards health professionals.

All of the patients seemed to be shocked that they had had a heart attack and eleven patients cited possible causes, which included aspects of lifestyle and heredity. Three patients seemed reasonably certain about the cause of their heart attack, whereas seven patients seemed uncertain.

There seemed to be four main ways in which patients were affected by their heart attack: being fearful of having another heart attack; feeling tired all of the time or becoming easily fatigued; wanting to get back to a previous level of functioning; and finding it difficult to take in all of the information given. The analysis of the data concerning these patients' perspectives on treatment for heart attacks will now be discussed.

Chapter Five

Patients' perspectives on treatment for heart attacks: analysis of initial interviews

5.1 Introduction

This aim of this chapter is to discuss the analysis of the data from the initial stage in-depth interviews that concerns CR patients' perspectives on treatment for heart attacks. The patients' perspectives on lifestyle modification are discussed in section 5.2 and individual aspects of lifestyle modification are discussed in four subsections to show whether and how patients changed their lifestyle and what these changes meant to them. These aspects of lifestyle modification are stopping smoking (section 5.2.1), doing regular physical exercise (section 5.2.2), making dietary changes (section 5.2.3) and reducing job-related stress (section 5.2.4).

Patients' perspectives on medicines are discussed in section 5.3. This begins with a discussion about their approach towards taking medicines (section 5.3.1), followed by a consideration of the approach that they seemed to have taken towards medicines-related information (section 5.3.2). In section 5.3.3 discussion centres on patients' explanations for why they thought that medicines had been prescribed following their heart attack and in section 5.3.4 the involvement that patients talked about having with pharmacists is discussed. Key points are summarised in the final section of the chapter.

5.2 Perspectives on lifestyle modification

Table two summarises the aspects of lifestyle that patients perceived as causes of their heart attack (as discussed in section 4.4.1) and the lifestyle changes that they said they had made. Crosses indicate perceived causes that did not seem to have been changed and question marks indicate uncertainty over whether perceived causes were changed.

Table 2

Patient	Perceived lifestyle causes				Lifestyle changes claimed			
	Smoking	Exercise	Diet	Stress	Smoking	Exercise	Diet	Stress
R1	✓				✓		✓	
R2	✓	✓	✓		✓	✓	✓	
R3						✓	✓	
R4						✓	✓	
R5					✓		✓	
R6		✓		✓		✓		?
R8		✓	✓	✓		✓	✓	✓
R10	✓				✓			
R11			✓	✓			✓	✓
R12	✓			✓	✓			?
R13						✓	✓	
R14	✓		✓		✗	✓	✓	
R15		✓	✓	✓		✓	✓	✓

R3 and R5 did not talk about possible causes of their heart attack, and R4 and R13 talked about not being able to find any likely lifestyle causes. R7 and R9 are not included in this table because they did not talk about possible causes of their heart attack and did not actually say whether they had changed their lifestyles. R7 seemed to be highly anxious and spoke mainly about the impact that the heart attack had had on his life, as was discussed in section 4.5. However, his wife talked about being keen to

find out how to prepare low-fat meals, which implied that she had modified his diet. R9 conveyed the impression that he did not think he needed to change his lifestyle because he talked about doing regular physical exercise before he had his heart attack and said that he had only “skimmed through” the information on healthy eating and exercise but had been keen to read the rest of the information he had been given.

As can be seen from table two, the lifestyle changes that patients said that they had made tended to reflect the aspects of their lifestyle that they perceived as causes of their heart attack. Seven patients (R2, R5, R6, R8, R12, R13 and R15) talked about having made lifestyle changes in order to prevent another heart attack. For example, R15 said, “you carry on your lifestyle, your body’s saying look I’m not happy I’ve got a problem, if you don’t address the problem it will happen again won’t it...I want to make sure I don’t have another one” and R13 said:

“You can’t afford to have another one [coronary artery] go. One’s already blocked and you can’t afford to block one of the other ones. So it’s a question of adapting your lifestyle, perhaps doing this instead of that.”
(R13)

Five patients (R1, R4, R10, R11, R14) did not explicitly state that they had made lifestyle changes as a preventative measure but implied that they had because they talked about making changes to their lifestyle straight after talking about the likely causes of their heart attack. In contrast, R3 did not talk about possible causes of her heart attack and did not say or imply that she had made lifestyle changes as a

preventative measure, although this does not necessarily mean that this was not the reason why she talked about having made lifestyle changes.

Moral concerns also appeared to affect what patients said about lifestyle modification because they seemed to avoid presenting themselves as not attempting to prevent further heart attacks. This seemed to be shown in justifications for why changes had not been made. For example, R14 justified not having stopped smoking (a perceived lifestyle cause of his heart attack) by saying “I’ve tried to give up smoking but unsuccessful at the moment”. Similarly, R5, R9, R10 and R12 justified not doing regular physical exercise by saying that they intended to, even though they had not cited lack of exercise as a cause of their heart attack. In addition, five patients talked about lifestyle modification in more general moral terms. R6 talked about lifestyle change as a “responsibility”, R9 talked about an employee and a regular squash player who had had a heart attack being “as clean a living man as you could think of”, whilst R5 referred to lifestyle modification as being on “the straight and narrow”. R15 talked about a customer who had had a heart attack and was “more or less saying I’m ready for another one” because he had not stopped smoking and “heavy drinking”, whilst R12 talked about being given a “second chance” to look after herself:

“Now I know I’ve been given a second chance in one way and I can do all the things now to look after myself.” (R12)

In the following four subsections aspects of lifestyle modification are discussed in more depth to show how patients changed their lifestyle and what these changes meant to them. Consideration is also given to issues such as how fear of having another heart

attack seemed to have influenced the lifestyle changes that patients had made. These aspects of lifestyle modification are stopping smoking, doing regular physical exercise, making dietary changes and reducing job-related stress.

5.2.1 Stopping smoking

Of the six patients who said that they smoked before they had their heart attack, five patients had stopped but, as discussed above, R14 had not and justified it by saying “I’ve tried to give up smoking but unsuccessful at the moment”. R5 said, when talking about the changes he had made to his lifestyle, “I’ve cracked it with fags, I’ve really cracked that and the wife’s stopped as well” but did not elaborate further. The other four patients talked at greater length about stopping smoking and three themes emerged from what they said: how they had made the decision to stop; how they actually stopped; and how they were finding abstinence from smoking.

Whilst they were in hospital R1, R2 and R12 had made the decision to stop smoking. R1 said that he had tried to give up before but had always been tempted to start again. He pointed out that having a heart attack had been a shock and had “given me the kick up the backside that I needed to pack up smoking”. R2 said that since she did not want to have another heart attack, “you don’t want to encourage anything that’s going to give you that pain ever again”, with particular reference to smoking. R12 said that the consultant had said to her “it was up to me, you either smoke, smoking can kill you and if you don’t this cuts it by fifty percent”. As a result, she had been fearful that she might have another heart attack if she continued to smoke and so had decided to stop:

"I think it's the fear. Before, many times I have wanted to stop and you're having your cigarette and this is my last, I'm never going to have another one but I didn't realise I was having my last one did I!" (R12)

R10 had continued to smoke after he had his heart attack but explained that he had, "decided eventually that I'd eliminated everything else that could have caused the heart attack so that was the only thing I can put it down to". He had subsequently decided that smoking "had to go", although this had been a difficult decision for him, as he explained, "the problem was, yes I know I need to stop smoking but I don't want to if you know what I mean, I love my cigarettes".

R2, R12 and R10 talked about how they had actually stopped smoking. Having made the decision, R2 and R12 had subsequently just not smoked. R2 talked about it being a matter of "willpower" and said, "I haven't had any help, aids". R12 said, "after seven days in hospital I thought well if I can go seven days I can try a few more days" and by the time she went to the smoking cessation service she was told that there was "no point" in starting nicotine replacement therapy, since she had managed five weeks of abstinence from smoking. In contrast, R10 said that once he had made the decision to stop smoking he "went to the practice nurse to start", got some nicotine patches and went to stay with friends who did not smoke because the change in environment and routine made it easier for him to actually stop smoking:

"As soon as I got there then that was it. I'd taken my patches and they don't smoke up there. They don't object to me smoking but they don't smoke and I'd explained to them. I started it up when I got there and of

course I was there for a fortnight, just over a fortnight and the routine was so different.” (R10)

Three patients talked about the difficulty they were having in maintaining abstinence from smoking. R1 said, “on some days I could kill for a cigarette and other days it doesn’t bother me”. He added that “sheer willpower” had made him stop and he was taking it “one day at a time”, although he added, “you never know what’s round the corner; you might suddenly go and buy a packet of fags”. R10 said, “I’m still tearing my hair out” and, “sitting here now I could murder a cigarette; sat down with my coffee you know, it would be just heaven”. R2 said, “you know it does get like now, have a coffee and you’d fancy a cigarette, wouldn’t you, in the morning a cigarette with your coffee”. Her strategy to deal with this temptation was to remind herself of the pain she had experienced when she was having a heart attack:

“I’ve got a story I tell myself you see. It’s you’ve got this awful pain and if you know what that’s like you don’t want another cigarette, you don’t want to encourage anything that’s going to give you that pain ever again!” (R2)

In contrast, R12 talked about the benefits she had found from abstinence from smoking, as she said that her “chest feels ever so much better” and she had realised how smoking had “ruled” her life and limited where she chose to go:

“It’s’ ridiculous isn’t it, when I think how it ruled my life...and you can’t go so and so coz I can’t smoke in there and I can’t do this coz I can’t smoke there. Oh no I can’t go on a long journey because I can’t go all that way

without a smoke, oh my God this is so ridiculous [laughs]! You don't think of it at the time as being ridiculous but I do now." (R12)

5.2.2 Doing regular physical exercise

Patients talked about physical exercise in three main ways: what they had done in the first six weeks after discharge from hospital before they had started the CR programme; the physical exercise that they had done on the CR programme; and the physical exercise that they were currently doing (i.e. after having attended the CR programme). However, not all of the patients talked about physical activity in all three of these ways.

Whilst they were in hospital all of the patients had been given a booklet by the CR nurses that recommended how they should gradually increase physical activity in the first six weeks after discharge from hospital. The booklet explained that in the first week after discharge they should avoid strenuous activity and should restrict themselves, for example, to light dusting, and by the sixth week they could, for example, mow the lawn. Five patients specifically talked about this six-week period. R9 said that he had been given "a list of what I should do, you know a six week programme of what I should do", which had specified "what goal I should be trying to achieve". R3 said that she had been given "a letter that said what to do on the first week and the second week" and talked about the recommended amount of walking, "you know the first week for ten minutes and the next week fifteen minutes and so on". She added, "by the sixth week I was supposed to be able to mow the lawn". R1 said that he had done more walking than recommended because "they said five minutes a day but when I take the dogs out they won't stay out for just five minutes". He added that he had not felt any "ill effects", since it was not "as if I was running round the field with them" but it had got him "out of

the house” into the “fresh air”. R10 said that he had done “the walking like they said” but, as discussed in section 4.5.1, talked about “a fear in the back of your mind that you were frightened of doing something that’ll bring it on again” and so had not done “anything that I imagined would put strain on my heart”. R13 had also been fearful of doing anything that might cause another heart attack:

“I think it was being anxious to know how far you could actually push yourself without supervision. For the first six weeks all I did at home, we went for walks because that was what the books said, light dusting and all that nonsense! By the six weeks we were walking more and more so probably by the six weeks we were walking two to two and half miles a day. But that was it. I wasn’t doing any sort of running or exercises or anything else physical. Certainly hadn’t lifted anything at all.” (R13)

Nine patients talked about the exercise component of the CR programme and only talked about the education sessions when prompted, which suggested that they viewed the programme as being primarily about exercise. R6, R8, R11 and R13 talked about both the exercise component and the education sessions without prompting. In contrast, R1 only talked about the education sessions and R7 only mentioned that he had attended the CR programme. Five patients talked about the exercises that they had done on the CR programme as having reassured them that they could do strenuous exercise without having another heart attack, whereas seven patients talked about the exercise in more general terms such as that it had been “good” for them. In contrast, R3 only said, “I do find it, well not a strain but it’s not natural” and did not say whether or not she had thought it to be beneficial.

Of those patients who talked about having been reassured that they could do strenuous exercise without having another heart attack, R11 said that he had been reassured because “the actual physical activity was fine yes, I had no problems”. R5 said that he had been reassured because he had not “suffered any ill effects, chest pains or anything like that” and other than that his legs “have felt like somebody else’s” he had been “as right as rain”. R13 and R12 had been reassured because the exercise had shown them “what you could do” and R12 added, “after that it gets a lot easier, you don’t worry anymore quite so much”. R10 said:

“You’re sort of worried about it, doing something that’s make it happen again of course. I found personally it’s been allayed somewhat by going to these exercise courses, realising how physical you can get without having, you know, bringing another attack on because you imagine, and I certainly did as much before I came, that it could be fatal.” (R10)

Of the patients who talked about exercise at CR in more general terms, R6 said that the exercises were “very worthwhile”, R15 said, “it has been useful for me” and R14 said, “I enjoyed going to it like, it was helpful I think, I mean at the moment it’s just got me into the exercising and what not”. R4 and R8 said that the exercise had made them “feel better” and R9 said it had made him feel “good”. R4 added, “I feel and I’m sure I’m fitter” and R2 said:

“Doing my exercises. I do think that aspect of it has really made a difference. The physio, it’s not much fun doing it. God, you think it’s so exhausting and at the time you think I’m never going to do this and then

you do it. You do it because you know it's good for you and you've really got to do it." (R2)

Ten patients talked about the exercises they were doing after the CR programme in terms of wanting to continue doing regular physical exercise. R6 said, "I in fact do the programme at home" and pointed out that she preferred to do this rather than going to "exercise class" or "going out into the street and doing it" because exercising in private meant that she could "make a complete fool of myself and only the cat knows". She added that she "felt safer doing something I know people with a certain knowledge have authorised", rather than "wearing myself out doing something that Jane Fonda says is good for you". R13 said, "I do exercise specifically now certainly" and added, "we've always walked but now we actually exercise". R14 said that he was "trying to do a lot of walking" and R11 said that he had "been cycling" and "walking a lot". In his case he had not changed his lifestyle because doing regular physical exercise (e.g. playing football regularly) and keeping "fairly fit" was something he had also done before he had his heart attack. R8 talked about having made "massive changes" to his lifestyle in order to do more physical exercise:

"You know I've made a lot of massive changes really you know...So we decided, right we'd sell the house and move to not that far away but a different location where there's lots of walking, space you know, very sort of countryside and picturesque for walking. So you know, hence we do lots and lots of walking and keep that up...as a family do things together much more and be more active rather than, you know like days out at the seaside in the sun and stuff like that. Again in the physical activity that we

would be doing rather than sitting around the telly or playing on the Playstation, stuff like that.” (R8)

Three patients said that they were doing regular physical exercise but wanted to do more. R9 said, “I’ve always been an active person” and added, “ok I go and play golf every day but you need something else”. He said that the exercises on the CR programme had made him “conscious that I probably want to get involved in some sort of regular exercise” of a similar nature. This was a view shared by R10, despite having previously “pooh poohed the idea of gym exercise”:

“Yes I’ve quite enjoyed the exercise. As I say I’d always pooh poohed the idea of gym exercise, you know it wasn’t what I thought was fun but I must admit I’ve quite enjoyed myself. It soon goes by and I’m contemplating looking at going for exercises at a gym.” (R10)

R4 said, “I’m exercising a lot more, in that I’m purposely exercising” but he wanted to “do more” and talked at length about wanting to get “exercise on prescription” from his local GP (an initiative involving a course of twelve supervised exercise classes at a local gym). He said that he wanted to try this rather than just going to a gym because the staff would be aware that he had had a heart attack and may have a “specific regime” for people in his situation. His concern with just going to a gym was that he was “sure you can catch a bug with this gymnasium type of thing” and that this might result in him “going like the clappers”, which “maybe I shouldn’t do”. As such, it seemed that whilst he was fearful that an unsafe exercise “regime” might cause another heart attack,

his main reason for wanting do more exercise was because he was fearful of having another heart attack if he did not.

Two patients (R2 and R15) talked about wanting to do regular physical exercise but had difficulty doing it. R2 said, “I can walk from A to B but I can’t do long walks” because of her “degeneration of the spine and arthritic knees” and, as discussed in section 4.5.2, became quickly breathless and “wiped out” on exertion. However, she added that this had not stopped her from exercising completely and gave a number of examples of occasions when she had parked her car further away from where she was going than she needed to so that she had “walked deliberately”. R15 talked about exercising but explained how he found it difficult to fit in around working full-time and family commitments, particularly since he felt so tired (as was discussed in section 4.5.2). The way he talked about this seemed to reflect his general state of anxiety (section 4.5) and gave the impression that he was fearful that not doing more exercise was making it more likely that he would have another heart attack:

“It’s difficult to find the time to replicate the exercises, the lassie said today about so many sessions, I know I have got it to do but the practicalities when you have been busy at work and you’re really tired, you come in and you help to prepare the evening meal and you then don’t want to be doing any of this and I made sure I have found time three or four times a week to do half an hour on a bicycle, some step ups. When I was at home I was walking everyday but I just don’t have the time to do the walking because of family commitments and other things in your life beside work. But you somehow I’ve got to get into the discipline of doing more exercise than

what I have been doing. I have been doing some but clearly not enough but it's finding time to do it. I can't do it when I come from work, can't do it immediately after I've eaten because I don't think that is a good time to do it, so I've just got to find time to do it." (R15)

R3 also talked about exercising but conveyed the impression that she was less than keen. She said that it was difficult for her to exercise because "I've never been a fast walker have I really, I blame little legs really" and explained that this meant that she had to take more steps to keep up with people who were "fast walkers". She added that having retired from running a playgroup where she had "to be on the move" may have meant that her "body says oh well you've retired from that so we're not rushing about so much". On the subject of doing exercises after CR she said:

"I do keep trying to do some, I mean I don't do an hour at a time or anything like that at home but last night at about quarter past eight I did a good quarter of an hour, you know and you tend to do nearly the same thing again and there again if it's so many of these it should be helping shouldn't it, you know. I mean I don't go round and round the table. On the spot and do something else and then on the spot again and do something else, you know with my hands or my feet or what have you." (R3)

She also said why she had not been to go to any exercise classes at the local gym. Her reasons included that she was unable to get there because her husband was often unable to drive her there, that her friend that she had intended to go with was not well at

the moment and the only alternative was an exercise class in her village, which she thought was fully subscribed.

In contrast, R5 and R12 did not give any indication that they were doing regular physical exercise but said that they intended to do so. R12 said, when talking about losing weight “I now know that I can go and exercise so that helps as well” and R5 said:

“I shall certainly have to start doing some of it at home. Yes, some step-ups and things like that. I’ve got an exercise bike but all I need to do is go for a walk isn’t it.” (R5)

5.2.3 Making dietary changes

As discussed in section 1.2, patients were advised to eat a balanced diet. Eleven patients talked about dietary changes they had made, or not made, but in terms of “cutting things out” of their diet, rather than eating more of some foods (for example, fruit and vegetables) and less of others (for example, those that are high in fat, salt and sugar). Six patients talked about specific foods they had “cut out”. R14 said that he was “trying to cut out fatty foods”. R13 said that he and his wife were now “certainly aware of what the contents of packets are” and had “certainly cut down on a lot of things, cut down on unnecessary things”. This was because of their heightened awareness of “what fat is in things and other things in packets” so that they could “try to eat healthily basically”. He added, “we always have, just even more so now”. R15 talked about not eating too much and reducing his consumption of fat, sugar and alcohol:

"I'm cutting out puddings and sugary things, fatty things so I'm being more careful with my diet...I'm not a big drinker but occasionally I have a few extra and I'm trying not to do that. I'm finding it very difficult to have alcohol-free days, as I like a little glass of beer with my evening meal and I used to have a glass of whisky at night but I don't now, I won't touch it now. So it's teaching yourself, be sensible about this." (R15)

R11 said that he had reduced his "fat intake a lot" by having "switched to semi-skimmed milk" and no longer eating "fatty foods or anything like that and we don't eat cakes". He talked about having made these changes to reduce his cholesterol, which he had perceived to be a cause of his heart attack. R2 and R5 talked about the specific foods they had "cut out" of their diet as being "bad" foods or foods they "can't have", rather than giving a specific reason for dietary change. R2 talked about being a "great cheese eater, absolutely loved cheese, all sorts, particularly soft cheese and things that are bad for me, you know" and added, "now I only eat it occasionally, not much". R5 talked about not having not been aware of the "damage" that certain foods may have done and recited a list of foods that he "can't eat" any longer:

"You only want to know these sort of things when it's happened to you and it is thrust upon you but it's needed to be thrust upon you. And you have got to digest it, there's no two ways about it. There's stuff you can eat, there's stuff you can't eat and I didn't realise what damage some of the stuff were doing to you. You know like milk, we never had full fat milk for years anyway but I've always had sugar. And I love cheese and I love fry-ups. I don't have them any more. I don't have sugar, I have that, I tried

them Hermasetas. [Grimaces]. What I'm trying is now is that Silver Spoon one, it's very fine, it looks like caster sugar but it's alright....but it puts a scum on top of your tea, it puts you off...But it's better than nothing because I've always had a sweet tooth. Chocolate I can't have, I can't remember the last time I had chocolate. I literally stop with biscuits. I have digestive biscuits and I presume they're ok to have like...Oh yes, fish and chips, I haven't had them since well before Christmas [he had his heart attack on Boxing day].” (R5)

Three patients talked about “cutting things out” of their diet in more general terms by talking about losing weight or eating less. R1 said that he was trying to lose weight but was “having a hell of a job ‘cos I keep nibbling at things”, as a result of having given up smoking. R12 said “now I’ve got to get my weight off” and R3 said, “I’ve just got to carry on eating sensibly and try to eat just a little bit less”, as a response to her uncertainty about the amount of carbohydrates she should be eating:

“The dietitian was saying, you know, what to do when you’ve had a heart attack, sort of thing you should be eating but to me that was the same thing as I had been told for diabetes, I’m diabetic as well. The only thing I find is to do with the cholesterol, they do say that you need a certain amount of carbohydrate because it helps make cholesterol or it stops it or something or other, something about it! And you see if you want to lose weight the first thing you try to do is cut out carbohydrate. So if you cut out carbohydrate does that mean you’re going to make your cholesterol up?

So to me, I've just got to carry on eating sensibly and try to eat just a little bit less but still have some carbohydrate.” (R3)

In contrast, two patients justified why they had not made dietary changes in terms of not needing to “cut things out” of their diet. R6 said, “diet has never been a problem because I always enjoy what happens to be good for me”. She added that she occasionally ate foods such as red meat or chocolate but not “every day by any means, I never have done”. Indeed, from what she had been told on the CR programme she had “realised I was allowed far more of these things than I had been having”, which confirmed her opinion that she was “operating with sense” as far as her diet was concerned. Similarly, R10 said:

“I don't think my diet is all that bad; I've not been to McDonalds or had takeaways. I eat a lot of meat, don't eat a lot of vegetables. I don't like vegetables but I have very little cooked in fat or lard or grease or anything like that. If it's cooked in anything its sunflower oil but yes it's quite heavily biased towards meat...I'm not exactly overweight...and as I say my diet isn't that unhealthy. I don't stuff myself with fried egg and bacon and things like that. Yes, I have them occasionally but I don't eat them on a daily basis. I don't eat things like beef burgers or stuff like that, not my idea of fun.” (R10)

Four patients did not actually say whether or not they had made dietary changes. R9 and R4 talked about being given information on diet but did not actually say that they had changed their diets. However, R4 seemed to be very keen to know exactly “what

you should be doing, this is what you shouldn't be doing" in relation to diet, which implied that he was keen to follow the recommendations. His particular concern in this regard was that "there's a lot of contradiction in what you read in the books and what the nutritionist comes and tells you". As examples of this he cited recently amended recommendations about egg and oily fish consumption that he had been told about at CR, which "contradicted" the written information he had been given. This seemed to reflect his level of anxiety (section 4.5), his uncertainty about why he had had his heart attack (section 4.4.2) and his fear of having another heart attack (section 4.5.1). R8 said that he had got "stuck in a rut" in a lifestyle that involved "all the wrong things really" such as "fast food", lack of exercise and job-related stress and talked about having "made a lot of massive changes" since his heart attack but did not actually say that he had changed his diet. R7 did not talk about lifestyle modification at all, although his wife talked about how they had gone to a local healthy eating day, where they had "picked up quite a lot of tips" and had watched a chef demonstrate how to prepare various low-fat meals, which implied that she had changed his diet.

5.2.4 Reducing job-related stress

Five patients cited job-related stress as a cause of their heart attack, although the reasons why they had been stressed, the way it had affected them and what they had done about it varied. R8, R11 and R15 talked in detail about why their jobs were stressful and their strategies to reduce their stress, whereas R6 and R12 seemed less certain about whether they had been stressed (as discussed in section 4.4.2) and did not talk about trying to reduce job-related stress.

R8 talked about his job being stressful partly because of the long hours but mainly because he was required to make difficult decisions. The effect that this stress had on him, as he explained, was that he would worry about whether the right decisions had been made. His strategy to reduce this stress was to take “a different attitude”:

“In terms of my job, I mean that’s going to be the same basically but I’ve certainly got a different attitude to it...It’s one of those, you know, you have to make the right decision and how do you know, you know. If you make a mistake one way or the other it can have very damaging consequences but I look at it as a project now where I can only do my best. And once I’ve done that it’s got to be over with, whereas before I would fret about or worry or, you know, reconsider and such like the decisions that had been made and go over it and over it and the next one would come in and you know. It would be just like a treadmill really. So I suppose one of the changes is that I’ve changed my attitude a great deal to life really in many respects.” (R8)

As discussed in section 4.4.2, R15’s job-related stress mainly related to the company he worked for being taken over by a larger company. He described his new employer as wanting “their pound of flesh” and that “you’ve got to be on your toes all the time” because “there’s always somebody watching to make sure you are”. He explained that his job was also stressful because of the introduction of new working practices, such as having to learn to use a computer, and because he found it difficult working as hard as his much younger colleagues. He said that this caused him to get angina, which meant that he needed to sit down, use his glyceryl trinitrate (GTN) spray and wait until his

angina had gone. However, he added that “working that out in practice” tended to be “a difficult thing” because he felt under pressure to continue working, since the company was often busy and “the customers were in your face all the time”. His strategy to reduce his stress was to “put myself first, if I have angina it’s no good carrying on I have to have the spray and sit down and get out of the way”. The way he talked about this conveyed the impression that he was fearful that if he did not reduce his job-related stress he was likely to have another heart attack, since he was generally very anxious and talked a lot about the difficulties he was having at work.

Unlike R8 and R15, R11 said that he intended to take early retirement and not go back to his job as a teacher, as a strategy to reduce job-related stress. He added, “the thought of not going back to work has made me much more relaxed I think”. He explained that his job had been stressful because as well as having a class he was also the exam secretary, “which was almost a job by itself”. Subsequently, he had worked long hours and felt that he got little respite from work:

“I was in school for quarter to eight, most days I didn’t get out until five or half past. I brought work home everyday, you know, and weekends and it was just continuous and you get that you can never switch off. There was always something: What’s happening next? What am I doing tomorrow, what am I doing the next day and the next day and it just was continuous, almost a twenty-four hour job. I wasn’t feeling very well for some time now and I’d wake up in the middle of the night thinking about what I had to do the next day. But the fact that that’s gone or will go is a big relief yes.”

(R11)

5.3 Perspectives on taking medicines

The rationale for the use of medicines following a heart attack has been discussed in section 1.2. In the following four subsections the patients' perspectives on taking these medicines are discussed in more detail. In section 5.3.1 the discussion focuses on how patients seemed to demonstrate that they were taking the medicines that they were prescribed following their heart attack. The discussion in section 5.3.2 mainly concerns disquiet about taking medicines and the approach that patients seemed to take towards medicines-related information. In section 5.3.3, discussion centres on patients' explanations for why they thought that medicines had been prescribed following their heart attack.

5.3.1 Taking the medicines

Whilst it cannot be said categorically that patients were taking their medicines, all of the patients indicated that they were taking their medicines and demonstrated this in one or more of four ways: by specifically pointing out that they were prepared to take them; by talking about having a strategy to remember to take them; by showing that where doses had not been taken as usual, this had not been intentional; and by tolerating or seeking medical advice about side effects, rather than simply deciding not to continue taking the medicines thought to be responsible. Four patients specifically pointed out that they were prepared to take their medicines because they recognised the benefits of doing so or because they were expected to do so: R10 said "I just shove them in and do as I'm told", whilst R2, R3 and R5 said:

"I'm taking them because I know that they are good for my heart. You've got to be sensible about it haven't you. I don't resent taking them. I've had

the heart attack so I've got to have the drugs. It has been explained to me by the Consultant also the pharmacist was very good in his explanation, and I know I've got to take the drugs. That's it, you know. No objection to taking them at all if they're going to improve my heart that's all that matters. I don't want another heart attack, it's a very scary experience."
(R2)

"I mean I know it would be nice if I wasn't taking any at all but I mean, quite obviously what I've been prescribed is supposed to be helping me, so therefore it's up to me to keep taking them isn't it; keep taking the tablets." (R3)

"If they're put in front of me and somebody says you have got to take them, you'll take one of them, one of them, one of them, two of them in the morning and one of them and one of them at night, I sort of go into robotic mode and say right well I'll have that, that, that and that in the morning and that and that tonight. They've not given them to me for nothing. There's got to be a reason they've given them to me so I'll put them down my neck as long as they say I've got to do it." (R5)

Eleven patients talked about having a strategy to help them remember to take their medicines. This involved either taking the medicines at the same time of day each day (i.e. having a routine), using a physical aid (such as a Dosette box or a Medi-dose box), using a visual aid (such as placing the medicines in a particular place) or a combination of these measures. Five patients talked about having a routine for taking their

medicines: R3 said “a lot of them I can take in the morning and I usually work it in with breakfast” and R8 said that he had a “set time” and that “at nine AM I take the medication and basically it’s done then”. R12 said “I take them after having my breakfast”, R15 said “as I am eating my breakfast I just take them slowly” and added “when I go home at night I, with my meal, I take this Lipitor”, whilst R1 described his routine in detail:

“I get up in the morning and have a wash and do my business and that, put the kettle on, while the kettle is boiling I’ll get my medicines ready and my blood things ready and I sit in the front room, do my bloods, write them down, drink my coffee and take my tablets and then have my breakfast and then the same again in the evening.” (R1)

Two patients talked about using a physical aid: R9 said “I must admit the wife bought me one of those things to lay the whole week out in front of me” and R10 said:

“I had horrors when I got this big bag from the hospital, I thought how the hell am I going to sort these you know, what to take when but what I did was I popped into [chemist] and got one of those pill organisers and filled the thing up for the week and then it’s no problem.” (R10)

Two patients talked about combining a routine with a physical aid: R7 described taking his medicines at the same time of day each day and added “I just put them in my little things that I got, you know with little compartments”, whilst R11 said “I’ve got one of those gadgets to put them in” and added:

"I get up in the morning and come down and while I'm having breakfast I take the three and then I take two in the evening about the same time, about seven or eight o'clock." (R11)

The other two patients talked about their medicines being placed in a particular place to help them remember to take their medicines at the same time each day: R4 said that his wife got up earlier in the morning than he did and "straight away she'll get them ready. He would then see the medicines when he got up, which helped him to remember to take them. R13 explained how he used his medicines as a visual aid in detail:

"They were on the side next to the teapot so most of them were to take in the morning with breakfast so the first thing I did was to actually get them out. The difficult one is that they want me to take one of my tablets in the afternoon now, that's going to be the problem now. As long as it's in my face I'm alright so it's just on my computer at work till I get used to taking it then. So it's just doing things like that to remind me. And they are always in my face in the kitchen; the first thing I see on the bench is the five boxes of tablets." (R13)

Eight patients indicated that they had been taking regular medicines before their heart attack for the medical conditions shown in table one (section 4.2). R3 took metformin, gliclazide and acarbose for diabetes, and used inhalers for asthma. R4 took atenolol for high blood pressure and atorvastatin for high cholesterol. R7 took various medicines for spondylitis, high blood pressure and diabetes. R9 took atenolol and a water tablet for

high blood pressure. R10 took a tablet containing a combination of atenolol and chlorthalidone for high blood pressure, and peppermint oil capsules and mebeverine for irritable bowel syndrome. R11 took tamsulosin for a prostate problem, R13 took amlodipine for high blood pressure and R15 took lansoprazole for indigestion and heartburn. Of these four patients, three (R3, R7, R13 and R15) talked about incorporating their new medicines into their existing strategies for taking their medicines, whereas the other four patients talked about how they had changed their strategy because of their new medicines. R9, R10 and R11 had started to use a physical aid, whilst R4's wife had started to help him. R9 also used his physical aid to help him to avoid making mistakes, since he had "got in a muddle the first time". He explained that this was because of frequent changes in the packaging or appearance of his medicines, as a result of being given different brands of the same medicines. R4 described an alternative way of preventing mistakes, since he found that his medication changed frequently and so kept discontinued medicines in a separate place to distinguish them from his current medicines:

"As we see the GP, the GP changes tablets then we straight away take that one out of the equation and move it into somewhere else" (R4)

Five patients talked about instances where doses of their medicines had not been taken as usual but pointed out that this had not been intentional. Of these, four patients explained that they had realised later in the day and had taken them then, so that they had not actually missed a dose. R3 said "it's only about once that I've forgotten" and explained that this had "only" been a dose of metformin, rather than all of her medicines. She pointed out that in this case she had been able to "work it out and have

it later on and still take the three in the day". R7 said that if he forgot to take his tablets at night he always realised because:

"I think, I can't get to sleep, oh yes I haven't had me tablets have I, I can't get to sleep if I haven't had my tablets." (R7)

R11 said "I've never missed any, I've only once or twice I've forgotten them until later in the morning". R12 said that she was now "having to make the effort to make breakfast to have my tablets" (even though she did not like having breakfast) so that she could take her aspirin after food but:

"Sometimes if I don't have breakfast I don't take them until nearly dinnertime. Sometimes I forget to take them, get them all ready and then rush off to work and think Oh God, tablets I forgot to take them." (R12)

She pointed out that "you do remember eventually during the day", meaning that these doses had been delayed but not missed altogether. In contrast, R14 did talk about missing doses altogether when he said that he thought that his ramipril was "upsetting my stomach" because:

"Sometimes I forgot, you know, forgot to take it and I was alright like and other times when I'd been taking it, it was upsetting me so." (R14)

He explained this by pointing out that he was “taking them as regular as I can like, just odd times I forget like” and added “the ones I mainly forget are the ones I take at night, you know sometimes you’re that tired”.

The fourth way that patients demonstrated that they were taking their medicines was by tolerating or seeking medical advice about side effects, rather than just deciding not to continue taking the medicines they thought were responsible, before or without seeking medical advice. Twelve patients talked about experiencing side effects from their medicines, of whom eight patients seemed to have tolerated all of the side effects that they said they had experienced, whereas four patients said that they had sought medical advice because they had been unable to tolerate particular side effects. In contrast, R3, R9 and R10 did not talk about experiencing side effects of their medicines.

Of the eight patients who seemed to tolerate side effects, R1 and R5 talked about having ACE inhibitor-induced cough. R1 said “I’ve got this tickly little cough, I’ll just have to put up with it”, whilst R5 mentioned in passing about “that ramipril and the ticklish cough”. R7, R11 and R15 talked about feeling much more tired than they had before the medicines had been started. R7 said “I just feel tired”, R15 said that when he first started taking the medicines he “found one or two little side effects” such as feeling “a little bit dopey, like tiredness” and R11 said:

“Certainly I’m more tired...the atenolol says one of the side effects was fatigue, tiredness, coldness of the hands and feet. I have noticed my hands get cold. I did buy a thicker pair of gloves actually as I felt they were, not bad but definitely colder.” (R11)

R6 said, “I don’t think I’ve ever suffered a side effect of anything I’ve taken” but then went on to talk about getting headaches every morning for the first four weeks after the medicines were started and later in the interview said about beta-blockers that “the downside is that they seem to reduce the libido”. Although she did not explain what she thought constituted a side effect, the inference was that she meant something that had a greater impact on her health than the effects she mentioned. R13 seemed to express a similar view when he said:

“I seem to be ok, I haven’t had any problems with the medicines and there doesn’t seem to be any real side effects. I had the odd headache to start with but they warned me about that, they said they should wear off and they did.” (R13)

R7 and R12 talked about their medicines causing them to feel dizzy. R12 said her atenolol “does make me feel a bit queer sometimes”, by which she meant “I do get a bit dizzy and a bit breathless I think after I’ve taken that one, for about half an hour then it settles down again”. R7 said that he had to “mind how you get up” because if he stood up too quickly after being sat down he felt dizzy:

“Because you’re blood’s thinner, you get up quick you have to be careful because you tend to [gestures falling over]. I’ve had a few frights since. I’ve had to sort of make myself slow down there.” (R7)

Of the five patients who had sought medical advice because of side effects, three patients were told to stop taking the medicines believed to be responsible, whereas one

patient was advised to continue taking the medicine. R2 said “the ramipril does make you feel weird, quite heavy and weird, not normal” and that “when I went back to the GP, he said take it when you go to bed because, if you’re going to feel weird, all those feelings will work off while you’re asleep”. She explained that the “weird” feeling stopped after a few weeks but she had been unable to tolerate the cough caused by the ramipril and gave a detailed description of how much she had been affected by it:

“I don’t sleep very well. I don’t know whether that’s got anything to do with the ramipril because you get that damn tickly cough that wakes you up. Very dry throat, mouth and throat...I know they’re using it mainly because it’s cheap, the fact that people have coughs I suppose they think, oh well they’ll shut up about them but if they’re like me they won’t because it’s very irritating and it’s not just a tickle, you get to retching in the end. It’s the only thing that stops it. It makes you feel sick.” (R2)

She said that she had told her Consultant “I don’t think much to this ramipril, it’s given me this cough, which is very irritating, it’s not satisfactory” and that she had asked “can’t we try something else”. At this point she had been prescribed losartan as an alternative and was due to start taking it when she had used up her supply of ramipril. R4 said that he had “been having problems with tablets, definitely”, which seemed to have started with the “one night I felt really poorly and dizzy and went to see the GP the following day”. He said that his GP had “knocked me off the atenolol and the ramipril straight away” and told him “we’ll leave those off, your blood pressure’s very low”. He explained that the following night he had chest pain and went to A&E, where ramipril was restarted because his blood pressure had “gone up again”. After this his GP had started

him on bisoprolol and increased the dose of his ramipril but he had been unable to tolerate the cough caused by the ramipril:

“When I was taking ramipril the cough was horrendous and I can’t describe just how bad that is, you know going to bed at night and you have maybe a minute and from then on you’re coughing, you get a little bit of a lull and you fall asleep and wake up coughing again. I was going to bed with water, extra strong mints and cough sweets all next to the bed and getting through them fairly quick during the night. It’s a horrible, horrible cough, so they eventually took me off the ramipril.” (R4)

Subsequently, his GP had tried two alternatives, candesartan and then losartan, but these had both made him “feel ill”, by which he meant that he “was getting quite a lot of discomfort, it’s not what I’d call [chest] pain but yes discomfort”. He explained that he tended to get this “discomfort” when he was “doing nothing” but not when he was exercising and that it was still being investigated to see if it was angina because “it seems the wrong way round”. At the time of the interview he had just restarted losartan but at a lower dose, after his GP had stopped it for a week “just to get everything out of my system”, and he was waiting to see whether this would also cause “discomfort”. R14 said “I had to come off the Tritace, it was upsetting my stomach” and explained that he had “had a word with the GP like”, who had stopped the medicine. R8 said that he had “felt a sense of really being slowed down” by his atenolol, which had been “really quite an unnerving experience”. He explained that he sought his GP’s advice about it and had valued being told that the feeling “doesn’t stay like that” and that he would “get

used to it". Subsequently he had continued taking the medicine and tolerated the side effect until "after about three weeks or so on the atenolol I felt normal".

"I needed that kind of advice and support certainly at that early stage because it was, I remember I had, the first day really in effect when I was home my wife had gone to work and I was looking after my young son and I'd taken the atenolol as prescribed, as I'd been doing, and boy, it was the first time it hit me! It slowed me to such an extent that I couldn't deal with looking after a child and you know sort of, so yes I needed somebody to say you know stick with it, it doesn't stay as bad as that." (R8)

5.3.2 Views about taking medicines and approach to medicines information

All of the patients reported that they had been given information about their medicines. The forms of written information that patients were most commonly provided with were: Patient Information Leaflets supplied with medicines; the British Heart Foundation (BHF) booklet about medicines (one of their series of booklets about CHD); and a booklet produced by the local CR service, which contained a section about medicines. In addition, all except two patients (R1 and R11) reported that they had been given verbal information about their medicines by at least one health professional. These included hospital doctors, nurses (particularly CR nurses), hospital pharmacists, GPs, community pharmacists and medicines-related information on the CR programme. It seemed that the information that patients were given tended not to be individualised and had only partly helped resolve their medicines-related concerns. Nine patients expressed a sense of disquiet about taking medicines, mainly by raising their concern about four issues: side effects; how long they would need to take the medicines for;

differences in the information between written sources of information or differences of opinion between health professionals; and, why doses of warfarin changed. In contrast, six patients (R3, R7, R8, R10, R14 and R15) did not express any disquiet about taking their medicines or talk about wanting more information about their medicines than they had been given.

Of the nine patients who expressed a sense of disquiet about taking medicines, three patients (R2, R4 and R12) raised concerns as a result of experiencing side effects. R4 said that he had read the leaflets he had been given but pointed out that he had difficulty remembering what all of his medicines were for because they had changed so much and wanted to understand why he had “been having problems with tablets, definitely” (which was discussed in section 5.3.1). He had subsequently taken a keen interest in knowing about all of the potential side effects of his medicines and said that he had not found the information he had been given particularly helpful because it had not given enough indication of the likelihood of getting any of the side effects listed. This had been compounded by there being so many potential side effects:

“If you read the instructions on the tablets or the descriptions then you’ll think you’ve got everything going and it’s all down to the tablets because there isn’t anything that isn’t covered on those lists...One night when I got reading, I don’t know which one it was but I must have been in a good mood because I started to mimic all the side effects and it covered absolutely everything, you know, constipation to diarrhoea!” (R4)

He added that it seemed that the leaflets were aimed at keeping the manufacturers “out of trouble” by listing all the known side effects, rather than providing useful information for patients. The underlying significance of this was that the information had not helped him determine whether or not his “discomfort” was a side effect of the alternative medicines, whereas he had been able to “quickly pick up on” the cough being a side effect of the ramipril. The situation became more confusing when he was later told that losartan “doesn’t work as well as the ramipril” because this made him wonder whether this was why he was getting “discomfort”, rather than it being a side effect. This had prompted him to seek information that compared losartan to ramipril from the Internet and he talked about having found a “long-term study” in which “losartan won hands down” but seemed rather sceptical about this finding:

“The reports or the studies that they’ve done in the main say yes the losartan is a lot better than ramipril but then again most of the studies have been done by the people that are actually making the drug in the first place.” (R4)

He qualified this further by saying that “they can’t lie but they can look at the results and push the bits they like and push the bits they don’t like to the back”. The problem was that it still did not account for why he was getting “discomfort”. He said that it was “a case of try that tablet for a week and see how you feel”, which had been a lengthy process that he found particularly frustrating because, as discussed in section 4.5.3, he wanted “to get back to a little bit more of a norm” and “get back to work”. He said that when he had asked his GP when he could go back to work he had been told “well we’ll give it a couple more weeks and we’ll see” and the information about his medicines

failing to adequately explain why he had had these problems had only added to his frustration and anxiety. R2 said that a pharmacist had told her “all about the drugs, what the drugs did, why I was having them and all the rest of it” while she had been in hospital and that she had also been given a booklet about medicines. She said “I don’t know whether other people read their little books or not, I read mine” and made the point that:

“I think that people like to be more aware than they’re given credit for. I don’t think there’s this blind acceptance anymore. I think that they do want, well me personally I do. I want to know what they are and what they do.”
(R2)

She particularly talked about wanting to know the likelihood of getting side effects from her medicines because, similar to R4, she had been unable to tolerate the cough induced by ramipril and was due to start taking losartan (as discussed in section 5.3.1). It seemed that this was mainly because she was concerned that she might also experience side effects from losartan. R12 said that she found that when she took her atenolol it made her “feel a bit queer sometimes”, as was discussed in section 5.3.1. This seemed to have been what had caused her to take more interest in why she had been prescribed atenolol than her other medicines and, as is discussed in section 5.3.3, subsequently found that the information she had been given had not helped her to understand why it had been prescribed for her.

Three patients (R5, R11 and R13) talked about wanting to know how long they would have to take their medicines for, which suggested concern about the potential to be

taking medicines indefinitely. R13 said that a pharmacist had spoken to him about his medicines while he was in hospital but added that he had wanted to know “what the thing does and you know why it’s there but the actual dosage, that’s for the pharmacy and the doctors to sort out”. When asked if there had been anything else he had wanted to know about his medicines, he said:

“Certainly for how long you’re going to have to take them. I accept that most of them I’ll be taking for the rest of my life, whether some of them will be tweaked or not I don’t know, but certainly I was told maybe six to twelve months, this is the basic time for drugs. So we’ll have to see what happens after that.” (R13)

R11 said “I’ve got the book, of course I’ve read the book and I filled out in the back of what I’m taking and why I take it and what they do” but added “I’m interested to know whether or not I can eventually reduce the amount of medicines I’m taking”. R5 said that he had asked his doctor what his medicines were for but indicated that he had had difficulty understanding the information he had been given:

“Well, my own doctor explained to me that, when I got my first repeat prescription. I queried about what like and said well. He did tell me what beta-blockers did. That’s something for strengthening the heart isn’t it? Another one, it’s a pinky colour, I only take one of them now but that’s something to do with lowering your cholesterol along with another one that’s something to do with cholesterol or something for blood pressure, it’s double-Dutch to me”. (R5)

He talked about other patients at CR who seemed to know a lot about their medicines and commented, “that would do my head in, being a walking dictionary”. What he did want to know about was how long he would have to take the medicines for, which was shown when he was asked how he was getting on with his medicines and he said:

“Oh I’m ok, I can put them pills away. It’s waiting just how long I’ve got to take them, is it going to be forever and a day?” (R5)

R6 and R9 talked about having questions about their medicines because they were concerned about differences in the information between written sources of information or differences of opinion between health professionals. R9 said that he had read a book called “the heart or the healthy heart or something or another” that his GP had recommended and said that he “thought it was very useful and it covers all aspects” but added that this had caused “an element of uncertainty”, as he put it, over why certain aspects differed from his own circumstances. He said that he had gone back to his GP to ask about these:

“He [GP] advised me to read this book so he had to have the questions because a little bit of knowledge can be, not dangerous but confusing if you’re not careful.” (R9)

It seemed that this had not fully answered certain of his questions, such as that “it says nobody should really be on above seventy-five aspirin, well I’m on double that”. He knew that this was because it was what his consultant “recommends you know, it’s not unusual” but this still did not explain the difference to his satisfaction because:

“Yes, ok I’m on a hundred and fifty aspirin and it says seventy-five but does another seventy-five thin my blood another fifty percent then or a hundred, or is it that aspirin thins your blood to a certain degree and that’s it?” (R9)

He also said “it worried me taking eight different types of tablets” because “it does say in the book that the most tablets patients would normally be on is three or four tablets a day”. This seemed to have worried him because it did not appear to be consistent with having had a “mild heart attack”, as he said he had been told when he had been in hospital. In this case being told that “well these are for this and this and this you know, that’s not unusual” had still not explained this apparent inconsistency. R6 said that she felt that she had been “well informed about drugs”, although she pointed out that apart from GTN spray “I knew what the other things were for because I come across them everyday in my own job” as a podiatrist. She talked about being “not quite sure” why there was a difference of opinion between her doctors about whether she should be on a beta-blocker or an ACE inhibitor (as is discussed in section 5.3.3) and said that at her next “check up” with her consultant she intended to ask “should I come off the beta-blockers and go on to an ACE inhibitor”.

R1 said that he had “read the stuff basically” that he had been given about medicines and “the guff that comes in the boxes which tells you about the side effects and things like that” and said that he had wondered “if this one will counteract the other” but added “I suppose these doctors that prescribe it wouldn’t do it if they did”. What he particularly wanted to know was why the dose of his warfarin had been increased when he last went to have his “blood checked”, since “why they’re doing things” had not been

explained to him at the time. He said that he wanted information about “why you’ve got to reduce it, why you’ve got to increase it” so that he could understand why his blood was “getting thinner or if it’s getting thicker” in case there was something that he could do to help his “blood stay at that sort of level”:

“If it’s getting thinner or if it’s getting thicker, if there’s anything they can tell you, maybe I’m doing something wrong. Maybe I’m doing something wrong, maybe I should be doing something, I don’t know, maybe there’s something I can do myself to help my blood stay at that sort of level. I don’t know if you can or you can’t but they should be able to tell you, shouldn’t they.” (R1)

It seemed that the main reason why he wanted to know this was because he had been worried that his blood not being “at that sort of level” meant that there was something wrong with his blood that might lead to another heart attack. This in turn seemed to be related to his general anxiety and fear of having another heart attack, as was discussed in sections 4.5 and 4.5.1.

R4 and R13 also talked about medicines-related questions they had had, which had been answered. In both cases these concerned perceived inconsistencies in the information they had been given. R4 talked about having been given three separate pieces of written information on how to use his GTN spray, each of which gave a different recommendation (ranging from five to fifteen minutes) on how long to wait after the initial dose before having another dose, if he still had chest pain. As discussed in section 5.3.3, using his GTN spray tended to make him worry that he might be having

another heart attack and having differing information about how to use it seemed to have increased his anxiety about using it. In this case he had resolved the inconsistency by asking his GP, who had told him to wait ten minutes before repeating the dose. R13 said “the one thing that was strange was that they were concerned about my cholesterol, which isn’t high but they wanted to get it down”. He explained that he had been prescribed a statin that had then been stopped and he “actually had to establish that they had stopped it” because it had “affected the liver” such that there had been “enzymes showing on my blood tests”. This had led him to “take the initiative” to ask why he was not taking “cholesterol tablets”, which resulted in him being started on gemfibrozil. It seemed that his concern was about the apparent inconsistency in starting and then stopping a medicine for cholesterol, rather than why the doctors had wanted to reduce his cholesterol level in the first place.

In contrast, six patients did not express any disquiet about taking their medicines or talk about wanting more information about their medicines than they had been given. For three patients (R3, R8 and R15) this seemed to have been because they thought that they had been given enough information, whereas the other three patients indicated that, if anything, they had been given too much information. R15 said that he had been given a lot of information about his medicines and that “everything was explained to me thoroughly”:

“I had a visit from the cardiac rehabilitation nurse at home and she came to see me. My doctor has spent a little bit of time with me explaining what they all do. They’ve been very good. The pharmacist spoke to us [at CR], he was very interesting and the book is very interesting and then my son,

he's on the Internet and he's looked up all these tablets and come out telling me all what they do because I'm not on the internet. So there's a lot of information, which seems to me that patients weren't told at one time."

(R15)

R8 said that whilst he was in hospital the doctors had explained the medicines in terms of "take this it's good for you, it's going to do you good and it'll protect your heart" and that other health professionals had given him extra information about *how* the medicines could protect his heart. He said that the CR nurses gave him "a broader explanation", that his GP had said "you know this is standard medication really for someone who's had a heart attack" and that the written information he had been given and what he had been told at the medicines education session at CR had given him a "practical guide to what the medication is actually doing". He added that:

"It was good having that extra information, sort of gives it a second suit, you know, why I'm taking it, why it's actually having a beneficial effect."

(R8)

R3 explained that she had been given a BHF booklet about medicines, which she had found "very informative" and that she had been told "which ones were for what and why". She said as a result she was able to "pinpoint" that "this one's for your heart, that one's for diabetes and that". Of the other three patients, R10 said that that he "knew aspirin" before he had his heart attack and "what the effects of it were" because he had heard that "they'd started giving it to people who'd had heart attacks". He added that he had read the medicines-related information that he had been given but had since

forgotten it, had been confused about how the other medicines worked when he had read it and subsequently questioned whether he needed to know “what they’re doing”:

“I actually got all the boxes out and all the leaflets out of the boxes and read them all. I got myself ever so confused about what does what but yes I did read them all you know, what the side effects could be and so on, and any other particular side effects they mentioned. I couldn’t tell you what this one actually does and what that one does, although at the time I read what this one did and what that one did...Anyway, at the end of the day I’ve a good idea that as long as you’re feeling alright they’re doing whatever it is they’re supposed to do and do you really need to know what they’re doing.” (R10)

Similarly, R7 said that he had been given medicines-related information but added “they tell me but I forget”. He pointed out that “if he [doctor] tells me I’ve got to take a co-proxamol and amitriptyline for me neck that’s all I need to know, not what specific purpose it’s doing”, in contrast to his son who “if they give him an aspirin he wants to know what it’s made of”. As far as he was concerned “the people who should know about that are the doctors, they should know the milligrams and things like that, I say too much knowledge is dangerous”. R14 said that while he was in hospital he had been told about what his medicines were for but he could not remember “exactly what was said”. He added that he “had not had chance” to read the written information he had been given about medicines because “it’s just too much to take in”.

5.3.3 Explaining why the medicines had been prescribed

Patients were asked what heart-related medicines they were currently taking partly so that they could then be asked why they thought that individual medicines had been prescribed. Nine patients seemed to have difficulty remembering the names of all of their medicines. Of these, R1 and R14 remembered some of their medicines but said that they could not remember the rest, six patients produced a list (either a manually produced list or their repeat prescription) because they could not remember the names of their medicines, whilst R4 went to a kitchen cupboard and brought his medicines out. R7, for example, said that his medicines changed regularly and he was unable to remember them all, which was why he had a list:

“I’ve got a list in my pocket, I can never remember what I’m taking so she [wife] types me out a list. Every time I go home she has to type another one out because they’ve added something else on...I mean you go to your doctor and they say what medicines are you on and I haven’t a clue” (R7)

In R5’s case the reason why he had a list with him was not just because he could not remember all of his medicines, it was also so that health professionals would have an accurate record of his medication if anything were to happen to him. This seemed to be another indication of his fear of having another heart attack, as was discussed in section 4.5.1:

“I always carry the list about with me of the medication I’m on just in case anything does happen like, it’s there for anybody medical to see like” (R5)

When asked why they thought that their medicines had been prescribed, it seemed that patients mainly thought that they had been prescribed to help prevent further heart attacks, although some patients also talked about medicines aiding their recovery. Thirteen patients talked about why they thought that individual medicines had been prescribed. Of these only three patients (R2, R8 and R11) gave an explanation for all of their heart-related medicines, whereas the other ten patients gave explanations for some, but not all, of their heart-related medicines. In general, a greater proportion of patients taking certain medicines, such as statins, were able to give explanations than for medicines such as ACE-inhibitors. R7 and R15 did not actually give explanations for why they thought any of their medicines had been prescribed: R7 described the medicines that had been prescribed after his heart attack as “the new ones which are for my heart”, when referring to his list but did not elaborate further. R15 produced his BHF booklet about medicines and said, “if you said to me what do they do, I would have to look through here but at least I know”.

Four patients talked in general terms about why thought that their medicines had been prescribed. Three of these patients talked about the medicines preventing or protecting against further heart attacks: R1 said “basically they’re to protect your heart or something, as far as I know”, R8 said that the medicines were “protecting the heart” and R12 said “the drugs seem to work pretty well” because they were “keeping me well” (i.e. she had not had a further heart attack). R2 talked about the medicines aiding her recovery when she said that the doctors had told her that “the heart was damaged and it’s got to repair itself with the aid of drugs and rest”.

As discussed in section 5.2, patients tended to relate aspects of their lifestyle that they perceived had been causes of their heart attack to the need to change those aspects of lifestyle to prevent further heart attacks. In contrast, most patients did not talk about how the perceived causes of their heart attack related to how they thought that individual medicines could help prevent further heart attacks. Those few patients who did talk about this seemed to have found it somewhat problematic, which was shown in what they said about their individual medicines. This suggested that, for the most part, patients may have taken the explanations in the information they had been given at face value without necessarily considering how this related to their own circumstances. The exception to this was R11 who talked about having a high cholesterol level as one of the causes of his heart attack and that simvastatin had reduced his cholesterol level, which was how it could help prevent further heart attacks. However, he did not talk about how any of his other medicines prevented further heart attacks in terms of the perceived causes of his heart attack.

Twelve patients indicated (either by saying so or because it was included on their list) that they were taking aspirin, R1 said he was taking warfarin “for thinning the blood” instead and in two cases (R5 and R7) it was not known whether they were taking aspirin or not. Of the twelve patients who were taking aspirin, seven patients gave explanations for why they thought it had been prescribed, R14 said that he did not know and four patients (R6, R10, R13 and R15) did not give an explanation. The explanations given by patients were that it “thins the blood” (R3 and R9), that it made blood “less sticky” (R4 and R12), that it “prevents clotting” (R8), that it “clears up any little bits floating about” (R2) or a combination of these reasons, as was given by R11:

“I know the aspirin is to make your blood a bit thinner and less sticky so it can’t clot.” (R11)

All of the patients’ explanations about why aspirin (or warfarin) had been prescribed seemed to be concerned with preventing further heart attacks by making it less likely that another blood clot would form. However, none of the patients indicated that they thought their heart attack may have been caused by their blood having “little bits” floating in it or being too thick, sticky, or likely to clot.

Statins also seemed to be talked about in terms of preventing further heart attacks. Fourteen patients indicated that they were taking a statin and R13 said that his statin had been stopped and gemfibrozil prescribed instead, as discussed in section 5.3.2. Eleven of these fourteen patients gave an explanation for why they thought they had been prescribed a statin, R7 and R15 did not, and R14 said that he did not know. The explanation given by all eleven patients was that the statin reduces, lowers or “works on” cholesterol, whilst R13 talked about gemfibrozil being prescribed to reduce his cholesterol. More patients related the way that statins could help prevent heart attacks to a factor that may have been a cause of their heart attack than for other heart-related medicines. Even so, only three patients (R2, R4 and R11) specifically talked about their cholesterol level in terms of whether it had been a possible cause of their heart attack: As discussed in section 4.4.1, R11 said that one of the causes of his heart attack was that his “diet was too high in cholesterol” and pointed out that “the drug to help reduce my cholesterol and the low-fat diet has brought it right back down again”. As discussed in section 4.4.2, R2 wondered how she “would have been” had she been given medication for her “slightly raised” cholesterol two years prior to her heart attack,

whereas R4 questioned how his cholesterol level could have been a cause of his heart attack because he was already taking a statin to “control” it and it had not been “mega high”. R5 did not specifically say that he thought that his high cholesterol level had been a cause of his heart attack, although he implied that it might have been when he said:

“These special pills for lowering the cholesterol, I knew as much as that tabletop about cholesterol. I didn’t know if it got up as high as seven or eight like mine were that it was going to be a king-size problem. I’ve got it down now, well it’s down to four-point-nine I think, the last test, the last blood test I had.” (R5)

R8 said that his cholesterol level had been high, which was why he had been prescribed a statin but did not actually say whether or not he thought that this had been a cause of his heart attack. R6 and R12 specifically said that they had not had high cholesterol levels (as discussed in section 4.4.2) but did not offer an explanation for why they had been prescribed a statin. Similarly, R13 said that “cholesterol seems to be the one major thing in all the regions that’s a major cause of heart problems” but said he thought that it was “strange” that the doctors had been “concerned about my cholesterol, which is not high”. This suggested that he remained unsure as to whether “cholesterol” had been a cause of his heart attack and why it needed to be reduced.

Beta-blockers seemed to be talked about in terms of prevention of further heart attacks and treatment to aid recovery. Fourteen patients indicated that they were taking a beta-blocker but it was not known whether R3 was or not. Eight of these fourteen patients gave an explanation for why they thought that they had been prescribed a beta-blocker,

R7, R13 and R15 did not and three patients (R1, R10 and R14) said that they did not know. The explanations given were that beta-blockers reduce blood pressure (R4, R6, R8, R11 and R14), reduce the pulse (R6, R9 and R11), help the heart to beat (R2), strengthen the heart (R5), or reduce stress (R6). The explanations about helping or strengthening the heart seemed to be mainly concerned with aiding recovery, whereas the explanations about reduction of blood pressure or pulse seemed to be mainly concerned with preventing further heart attacks. However, none of the patients indicated that they had perceived that high blood pressure or pulse had been a cause of their heart attack. This point was specifically made by four patients: R12 said that she did not know why she had been prescribed atenolol (and wanted to know, as was discussed in section 5.3.2) because she thought it was “for high blood pressure” but pointed out that she had “never had high blood pressure”. R4, R10 and R13 discounted having hypertension as a cause of their heart attack because it was being “treated” (as was discussed in sections 4.4.1 and 4.4.2). In contrast, R6 talked about beta-blockers “counteracting the effects of stress”, which she had cited as a cause of her heart attack (as discussed in section 4.4.2). She said that her current GP “felt my blood pressure was up a little” but pointed out that “it never has been, so whether that’s something that’s changed recently or whether it’s old white coat syndrome I don’t know”. She explained that her pulse rate was “quite low” even on a small dose of atenolol and her current GP wanted her to take an ACE inhibitor instead to reduce her blood pressure, whereas her “first” GP had preferred a beta-blocker. In trying to rationalise why there was a difference of opinion between doctors (which was discussed in section 5.3.2) she said that, despite being “not quite sure”, she could “only assume that the different emphases that these tablets work on are considered more relevant” by different doctors. The emphasis that she considered was most relevant was stress and her

reasoning for why she had been prescribed a beta-blocker was that unlike ACE inhibitors:

“They prevent to some extent the action of things like adrenaline, and adrenaline is likely to be brought into play in stressful moments. So I think my first GP probably thought, well the effects of stress will be minimal if she’s on a beta-blocker.” (R6)

Like beta-blockers, ACE-inhibitors also seemed to be talked about in terms of prevention of further heart attacks and treatment to aid recovery. Eleven patients indicated that they were taking an ACE-inhibitor, three patients (R4, R6 and R8) indicated that they were not taking an ACE-inhibitor and it was not known whether R5 was or not. R4 talked about his ACE-inhibitor being stopped and an ARB started, as was discussed in section 5.3.1, and explained that the ARB was to lower his blood pressure. Four of these eleven patients gave an explanation for why they thought they had been prescribed an ACE-inhibitor, four patients (R3, R7, R13 and R15) did not and three patients (R1, R10 and R14) said that they did not know. This suggested that patients were more uncertain about why ACE-inhibitors were prescribed than aspirin, statins and beta-blockers. The explanations given were that ACE-inhibitors reduce blood pressure (R9, R11), open up blood vessels “so that there’s more easy flow of blood through the existing vessels” (R2), or that they “make the heart sort of constrict to help the blood pump through” (R12). As with beta-blockers, explanations about reducing blood pressure seemed to be concerned with preventing further heart attacks, whereas the other two explanations seemed to be concerned with aiding recovery.

Seven patients indicated that they were taking other heart-related medicines regularly, six patients indicated that they were not and it was not known whether R1 and R5 were or not. Four patients (R7, R10, R14 and R15) were taking clopidogrel, four patients (R3, R4, R7 and R13) were taking a nitrate, R7 was taking nicorandil and R13 was taking amlodipine. Four patients (R3, R4, R10 and R14) said that they did not know why these medicines had been prescribed and the other three patients did not give explanations. In contrast, R8 talked about other heart-related medicines that he was no longer taking regularly. He explained that after his heart attack he had started to get “angina really bad” that got progressively worse and his GP had tried various medicines to “manage the pain”:

“They tried different ones, you know, the calcium blockers and all the different kind of stuff, just trying to manage the pain. I mean it was effective, it certainly helped but it was, you know, always a case of dealing with the symptoms and not the cause really” (R8)

After he had a CABG “all the other, the calcium channel blockers and stuff that I didn’t need to have anymore” had been stopped and he was only taking medicines to prevent further heart attacks.

Twelve patients indicated that they had a GTN spray, whilst R1, R5 and R11 did not. Six patients did not explain why they thought it had been prescribed, whereas the other six patients indicated that they knew it was for chest pain and if it did not relieve the chest pain it meant that they needed to seek urgent medical help because they may be having another heart attack. Three patients’ fear of having another heart attack was

particularly shown in the way that they talked about using GTN spray: R10 said “it’s permanently in my pocket”, R7 said that if GTN did not relieve his chest pain “they forgot to put panic, phone the ambulance” in the written instructions he had been given, whilst R4 said:

“You know, I’m sure that I’ve been told or I’ve read that anxiety is one of the things that can cause your blood vessels to do that, to give you that pain and that’s when you need to use the spray. Once you’ve used that spray once it’s like a ticking bomb; if that doesn’t go off in ten minutes I’ve got to use it again and then after that you’re sort of thirty minutes away from being in A&E! Now if that doesn’t make you anxious nothing will! That’s why I hate using it, I really hate using it. But you know from time to time I have, and the other thing is once you’ve used it once, say after ten minutes there’s just a faint, you’ve got a faint pain there do you use it again or do you get on with it? Because once you’ve used it again as I say then that’s putting pressure on you.” (R4)

5.4 Chapter summary

Patients tended to change aspects of their lifestyle that they perceived as causes of their heart attack to prevent further heart attacks. Five of the six patients who said that they smoked had stopped and ten patients seemed keen to continue doing regular physical exercise. Eleven patients talked about dietary changes, but in terms of “cutting things out” of their diet. Three of the five patients who talked about job-related stress detailed strategies to reduce it.

All of the patients indicated that they were taking their heart-related medicines and demonstrated this in one or more of four ways: by talking about being prepared to take them; by having a strategy to remember to take them; by showing that where doses had not been taken as usual, this had been unintentional; and by tolerating or seeking medical advice about side effects, rather than simply discontinuing the medicines thought to be responsible. Nine patients expressed a sense of disquiet about taking medicines, mainly by raising their concern about four issues: side effects; duration of therapy; differences between information sources or health professionals' opinions; and, why doses of warfarin changed. Although many patients seemed to have difficulty remembering the names of all of their medicines, they mainly talked about them being prescribed to help prevent further heart attacks but also to aid recovery. Most patients did not talk about how the perceived causes of their heart attack related to how they thought that individual medicines could help prevent further heart attacks and those who did seemed to have found this problematic. This suggested that patients may have taken explanations in the medicines-related information at face value without necessarily considering how this related to their own circumstances. The analysis of the data from the second set of interview with these patients will now be discussed.

Chapter Six

Analysis of second interviews with heart attack patients

6.1 Introduction

The aim of the second stage of the study, as discussed in section 3.3.1, was to conduct a second set of in-depth qualitative interviews with the CR patients approximately nine months after the first interview (i.e. approximately one year after their heart attack) to explore any changes in their perspectives on CHD and treatment. This aim of this chapter is to discuss the analysis of the data from these second stage in-depth interviews with the ten consenting CR patients who had had a heart attack (R5 died approximately six months after the initial interview, and consent was not received from R1, R8, R12 and R14). Patients were allocated the same 'R' (respondent) number that was used in the initial interview.

Patients' ongoing experiences of CHD are discussed in section 6.2, which includes the ongoing impact of having a heart attack (section 6.2.1) and use of health services and patient groups (section 6.2.2). Section 6.3 concerns patients' perspectives on the risk of having another heart attack. This leads into discussion of patients' perspectives on risk reduction and lifestyle modification (section 6.4), and their perspectives on risk reduction and taking medicines (section 6.5). Key findings are summarised in the final section of the chapter.

6.2 Ongoing experiences of CHD

6.2.1 The ongoing impact of having a heart attack

At the beginning of the interview patients were asked how their health had been since the initial interview. The responses given by seven patients suggested that the impact of having a heart attack was considerably less than at the time of the initial interview, especially because they said much less about it than they had in the initial interview. Four of these patients (R4, R7, R9 and R10) appeared to be much less anxious or depressed than in the initial interview. As discussed in section 5.5, these four patients previously seemed to have been particularly affected in their everyday lives by having had a heart attack and so the extent to which this seemed to have changed was striking. The other three of these seven patients (R6, R11 and R13) had not previously seemed so anxious and subsequent changes in how their everyday lives continued to be affected by having had a heart attack were less striking.

In the initial interview R4 had seemed particularly frustrated that he had not “got back to normal” (section 4.5.1). The main reason why he had not gone back to work was because he had been experiencing “discomfort” or “aches that I had in my arm and in my chest”, which was being investigated to see if it was angina (section 5.3.1). He explained that he had had an endoscopy and had been told that he had a hernia and:

“That’s probably what the symptoms are that you’re getting, it’s all to do with the indigestion and what have you than it is with actual chest pain or heart pain or what have you.” (R4)

He added that subsequently “tablets started that way and then other tablets were knocked off and after that I was brilliant”. Shortly afterwards he had gone back to work and after a period of working part-time had resumed full-time work. R7 had also expressed his frustration in the initial interview that he had not “got back to normal” (section 4.5.3). This was partly because he became easily exhausted when trying to do activities that he had previously been able to do (section 4.5.2) and he said that at the time he had been “a bit uptight about things”. Since then he had had an episode of severe chest pain, had been admitted to hospital and had angioplasty with stent insertion. As a result of this he said that he only got “occasional” angina pains and was able to do more than he had previously been able to do without becoming easily exhausted. R10 said “if I’m doing something in the garden or chopping logs or whatever, I can’t do the same amount as I did before” but reported that he was “otherwise fine” and had had no chest pains or any other problems with his health. He said later on in the interview that:

“I just get on with my life as best as I can, you know. It’s not quite the same but it’s not all that much different, I just feel tired quicker than I did before. Now whether it’s my age or whether it’s the medication, whatever you know.” (R10)

R9 said that he had been “through a period of depression” after having his heart attack (see section 4.5.3) but had seen a psychiatrist who had “changed my tablets” and as a result “slowly I’ve come back more or less to where I was”. He talked about his sons having taken over more of the running of the business but said that he had still “got a

stake” because he was still a “trainee retiree”. He added that as far as his health was concerned:

“I’m back where I was before I had my heart attack and probably I’m as happy as I’ve been at any time in my life.” (R9)

Of the three patients who had not previously seemed particularly anxious, R11 had taken early retirement but said, “I’m not going to sit around, I feel I could do something useful” and was thinking of doing voluntary work. He said that he had had “no problems at all” with his health since and that in general having a heart attack “had an effect but I think I’ve adapted well”. R6 and R13 had both gone back to work, and had gradually resumed full-time employment. When asked, R6 said that she had had no further problems with her health and R13 said:

“I’ve been fine. I don’t know what effect the heart attack had on my body but I’m good a year on. I feel really good. I get the odd angina pain but it’s less and less and less and now it’s virtually non-existent.” (R13)

The other way that five of these patients (R7, R9, R10, R11 and R13) talked about the improvement in their health was by pointing out that they had used their GTN spray less than they had previously done or that they had not had to use it at all (c.f. section 5.3.3). For example, R10 said “it’s still in my pocket, still there but no never been used yet, always have it with me but not had it out yet” and R13 said “I thought there’d be times when I needed my spray but I really don’t have to use it”.

In contrast, it seemed that the impact of having a heart attack had not lessened so much since the initial interview for R2, R3 and R15 and their everyday lives continued to be significantly affected by it. This had been compounded in all three cases by other problems with their health. R2 still became easily exhausted (see section 4.5.2) and was still quite breathless “but not as much, but I have bad days and good days, particularly if I’m overtired”. She had also recently had two prolonged episodes of cellulitis on her legs, which she said “did knock me down”. She said, “I can’t do half the stuff I used to do, mind you am I being unrealistic, coz I shall be seventy-four in March” and added:

“Everybody kind of believes I’ve kind of got to that age. I’m young at heart, I don’t feel that age but I mean I used to fly about a fair bit before and so I’m probably inclined to overdo it a bit.” (R2)

In the initial interview she talked about getting “better” being a matter of “willpower” (section 4.5.3) but now talked about how her reduced ability “puts a strain on you, how you feel sort of thing, you know, so you think oh dear I can’t do this”. R3 had had another heart attack since the initial interview and gave a detailed description of what had happened, as she had done about her initial heart attack (section 4.3). She said that she now got “chest pain” and seemed to be much more breathless than she had previously been. She also said that she had recently started to get “pains” in her legs when walking, which had limited how far she could walk and “does annoy me”, although being told “all about it” by her GP had been “a help”:

“She said it was because my blood vessels are narrowing and when you’re walking your blood vessels want some more blood and can’t get it because it’s not fast enough and so it causes them to be hurting you see...at least I know that bit now so that’s a help. She said I should try to walk through it, I am walking further before I stop now.” (R3)

R15 seemed to be more anxious than in the initial interview and spoke at length about the problems he had since had with his health and the difficulty and uncertainty in his life, particularly concerning his job. His main problem seemed to be that he had recently had a series of “mini-strokes”. He said that his “stress and worry” had been “put down to a depression” by the doctors on his most recent admission to hospital. This had resulted in him being given “a course of tablets, which will help relax you” because “while you’re in this state of tension you’re not letting your body heal”. As a result of this and having the “mini-strokes”, particularly since his face was “still patchy”, he said that he had “lost a lot of confidence doing day to day things” such as “taking my appointments on” as a local Methodist preacher because “I felt inadequate”. He talked about still feeling “washed out and tired” (see section 4.5.2), especially in the mornings as if he had “been heavily drinking the night before” and that his angina had increased recently as well. Despite this he said “yet I can go at home four or five days when I can feel really, really I ought be working and I’m a fraud” for being on sick leave but then on other days he had “felt really ill”. He pointed out that he did not really want to go back to his job “but I need an income” and “there’s loads of jobs out there at minimum rates but I can’t manage to work on minimum rates”, which only further increased his anxiety about whether he would be able to go back to his job and, if not, what would happen:

"I have been worried about my job and worried about the future. At sixty-one with a medical record, which isn't a hundred percent, people aren't going to be falling over themselves to employ me." (R15)

6.2.2 Use of health services and patient groups

All of the patients, with the exception of R15, reported that they saw their GP less often than they had done at the time of the initial interview and when they did see their GP it was now only for approximately six-monthly checkups, which tended to involve checking their blood pressure and cholesterol. Two patients (R9 and R11) reported that they were still under the care of their consultant cardiologist but now only for check ups, whereas seven patients reported that they had been discharged from their consultant's care. The way that the patients spoke about having reduced contact with doctors and that this was now only for check ups suggested that this had been a significant milestone in their recovery. It seemed that this was because it had confirmed their own perceptions of their health having improved. This seemed to be so even for R2 and R3 whose everyday lives still seemed to be significantly affected by having had a heart attack but both had been discharged from their consultant's care. As examples, R6 said that her consultant:

"...just discharged me, he felt I was ok and that I was ok with being discharged into the care of my GP." (R6)

She even attached a note to the consent form to say that she had been discharged from the consultant's care. R7 said that his consultant had "struck me off his list" and in

relation to his heart, now only saw his GP for check ups. R4 said, when asked if he still saw his GP regularly:

“Not so much now, he was keeping a very close eye while he was trying to get the balance of the tablets right but now I tend to wait until he sends for me for cholesterol tests for instance.” (R4)

He added that he had been discharged from his consultant’s care and joked that it was a case of “don’t darken these doors again”. R9 said that he only saw his GP “when it’s essential, every now and again, I’ve had to go in to have my blood pressure checked, order my tablets” and that:

“Now it’s just the GP that I see, that’s all really. So as far as the hospital’s concerned the regular checks will get further apart I should think as each time I go to see him [consultant].” (R9)

In contrast, R15 still saw his GP regularly (i.e. every two or three weeks) and talked about having “got under at least three consultants” who had “duplicated or even triplicated” various outpatient investigations as a result of recently being “admitted four times very quickly”, although this was concerned with having had several “mini-strokes” rather than his heart.

In addition to having reduced contact with doctors since the time of the initial interview, it seemed that patients had had little, if any, contact with health services or patient groups in relation to their heart and minimal contact with other health professionals.

This seemed to have been because patients chose not to do so, rather than that they were unaware that they could. For example, there had been a resuscitation training evening organised by the CR nurses as an extra event that all patients were invited to but only four of the patients (R3, R9, R10 and R11) had attended. R4 and R6 said that they had been unable to go, whilst the other four patients did not mention that they had been invited when asked if they had had any further contact with the CR service after finishing the programme. R6 and R7 did point out that they knew they could get in touch with the CR service if they needed further information or advice. R7 said about the community CR nurse “it’s knowing I’ve got his number if I need it” and R6 said:

“I mean I’ve you know, the people I’ve had dealings with in the rehab group have always made it clear that they would be happy to see me again and talk things over with me if I ever needed to and the door has always been left open, which is nice. It’s reassuring when people are like that but I haven’t taken them up on it.” (R6)

None of the patients seemed to have become involved with any cardiac patient groups and six patients explained why they had not done so. R3 said that she “didn’t seem to get round to it”, whilst R7 said that he had changed his mind about going because the meetings were held in the evening and “especially in the winter...when the sun goes down I don’t go out”. R6 said that she had “just never got round to it, it’s my laziness again”. R11 said that he and his wife had “talked about it” but he had decided against it because meetings were held during the daytime and he did not know at that point whether he would be able to retire or whether he would need to go back to work. R4

said that instead he had “been on the British Heart Foundation website and what have you, time to time, I’ve used that and it’s very useful” and R10 said:

“I don’t particularly feel I need anything like that, I had no problems so I haven’t felt it necessary to follow up in any way.” (R10)

6.3 Perspectives on the risk of having another heart attack

For many patients, having a heart attack had been a frightening experience (section 4.3.3) that happened when they were not doing anything that they might have expected to bring it on (section 4.3), which seemed to have had a significant bearing on their explanations for why it had happened. Subsequently, patients talked about a variety of aspects of their lifestyle (as well as non-lifestyle factors) that they perceived had been causative factors (section 4.4.1), although many of them seemed to have remained uncertain about whether and how much any particular aspect of their lifestyle had been a contributory factor (section 4.4.2). It seemed that patients’ anxiety (section 4.5) and their fear of having another heart attack (section 4.5.1), or at least a keen desire not to have another heart attack, had been an important influence on their decision to initially make lifestyle changes because the changes that they made tended to relate to those aspects of their lifestyle that they perceived had been causative factors (section 5.2). Fear of having another heart attack if lifestyle changes were not made seemed to be particularly evident in how patients talked about stopping smoking (section 5.2.1) and reducing job-related stress (section 5.2.4).

In the second interviews, patients were asked whether they had thought more about what had caused their heart attack. Their responses suggested that there had often been subtle changes in their views on this since the initial interview, although many patients seemed to remain uncertain about the likely causes (section 6.3.1). Patients were then asked whether they worried that they might have another heart attack, which they tended to answer in two ways. Firstly, they talked about fear of having another heart attack and their responses suggested that they tended to be less fearful than they had been in the initial interview (6.3.2). Secondly, patients responded by talking about their perceived risk of having another heart attack. Unlike in the initial interviews, many patients seemed to have now assessed their risk of having another heart attack on the basis of damage done to their heart (section 6.3.3) and whilst all of the patients talked about their personal responsibility in attempting to prevent another heart attack, patients often also talked about chance or bad luck determining whether or not it actually happened (section 6.3.4).

6.3.1 Further reflections on the causes of the heart attack

Patients were asked whether they had thought any more since the initial interview about what might have caused their heart attack. The responses given by six patients (R2, R4, R6, R10, R13, R15) suggested that their view of the likely causes was broadly similar to what they had said in the initial interview but with subtle changes. Of the other four patients, R11's view of what he thought had caused his heart attack did not seem to have changed and three patients (R3, R7 and R9) had not talked about possible causes in the initial interview (section 4.4.1). Despite further reflection, eight patients (i.e. all except R9 and R11) seemed to remain uncertain about why they had had a

heart attack, six of whom had also appeared uncertain in the initial interviews (as discussed in section 4.4.2).

In the initial interview R6 cited job-related stress and lack of exercise as the “only” reasons she could “come up with” but had seemed uncertain about this (section 4.4.2). She reiterated in the second interview that she was inclined to think, “I’m not really the sort of person who gets heart attacks” because she did not have any “obvious predisposing factors”. Subsequently, it was “still a mystery” to her why the heart attack happened and said that she now tended to think “it was just a bit of bad luck”, rather than just being a result of job-related stress and lack of exercise:

“I find it’s still a mystery really as to why it happened, I mean I know that the most likely reason for most people is a clot caused by atheroma but erm I find that curious in my case because I have never had a high blood cholesterol level but then perhaps it, atheroma, can develop with relatively low levels...I just feel that I don’t have, because I don’t have the obvious erm predisposing factors like obesity, very high cholesterol levels, and family history, because I don’t have those factors I tend to think it was just a bit of bad luck rather than anything else.” (R6)

R4 said, “I still think about it, I never not think about it” but still could not explain why his heart attack had happened. The only explanation he offered was that “it happens I suppose”, which suggested that he also had subsequently attributed it to chance:

"I would love to know what caused it. Nobody seems to be able to give me any inkling of why it should have been. Yes I had a stressful job and I was on tablets for high blood pressure so they were treating me for high blood pressure. They were treating me for high cholesterol before so why it should come just as it did I really would love to know but nobody seems to be able to tell me. It happens I suppose." (R4)

R2 seemed to remain uncertain about whether her cholesterol had been a "causative factor" (section 4.4.2) but now seemed to consider this to have been a more likely "causative factor" than being overweight and not doing enough exercise, although she still thought that smoking had been a likely cause. R13 continued to wonder whether heredity had been a cause (section 4.4.2) but now considered that this was a likely cause, since his father "had a heart attack at fifty-three". R15 said "so how it came I don't know" and pointed out that he had had an angiogram several months prior to having his heart attack and had been told "you've not got heart disease, you've not got it, your arteries are wide open and clean and fresh". He explained that at the time he had had "dullish pains" that the doctors eventually "thought was indigestion" after the angiogram showed that his coronary arteries were "as clean as a whistle". He added, "I was perhaps a bit overweight" and questioned "was I eating the wrong stuff, I don't know" and talked about the "stressful situation" he had been in at work as being the most likely cause. This was similar to what he had said in the initial interview (section 4.4.2), although he made no reference to lack of exercise and consumption of strong coffee being possible causative factors. R10 responded by talking about not having "done anything" to "bring it on", rather than discussing possible risk factors (especially

smoking), as he had done in the initial interview (section 4.4.2). When asked whether he had thought more about why his heart attack happened he said:

“No I gave up thinking about that a good long while ago, I decided you know just to get on with my life...but I do think at odd times you know am I going to have another one, what caused that one, could it happen again anyway because I haven’t a clue what brought it on. You know as far as I can see I hadn’t done anything in particular that day you know.” (R10)

R3, who had not talked about likely causes of her heart attack in the initial interview, indicated that she did not really know what had caused her heart attacks when asked, although she wondered whether “stress is amongst it” because “we’d been going through a bit of a bad patch...and then it was only months later that it caught me up”. She explained that her second heart attack had happened when she had been going to go to an “auto jumble”, which had been stressful since “I hate selling the stuff because I don’t know what I’m talking about” and so she had not been “looking forward to it at all”. She also wondered whether stress had been a cause of her first heart attack because she and her husband had been taking their daughter and son-in-law to the airport and “you know it’s a bit sometimes you think, oh dear they’re going abroad”. R7 also did not talk about possible causes in the initial interview and when asked in the second interview what he thought had caused his heart attack he said “well we don’t really know, I mean we just went to church I sat in church and bang that was it”. However, he then added that prior to his heart attack he had “spent a lot of time just sitting about doing nothing you know” because of his back problems (see table 1, section 4.2) and “before it used to be chocolate, fish and chips, fry ups you know”.

In contrast, R11 seemed much more certain of what the likely causes of his heart attack had been and cited the same causes that he had talked about in the initial interview, which were discussed in section 4.4.2:

“The fact that it ran in the family, high cholesterol and work pressure were the minuses, the other things that increase the chance of heart attack were ok, you know.” (R11)

He then pointed out that he was not overweight, was fit and “didn’t smoke or drink much”. R9 had not talked about possible causes in the initial interview but now said:

“Hereditary, yes a lot of the family have it, my belief at the end of the day is that eighty-five percent of these problems are hereditary and the other fifteen percent will be lifestyle. It could be affected by your lifestyle but I’ve been an active chap all my life, I’ve never been scrawny but I’ve never carried a lot of weight. You know I was brought up on a farm and I had a good balanced diet. Never seen the inside of a McDonalds so to speak so I think majority of it comes from hereditary if you look at it coz there are five of us in the family and three of us have got problems. My younger sister takes more or less the same tablets as I do and she’s not had a heart attack and it only came through by the fact that she had been checked over and they found the problem so.” (R9)

6.3.2 Fear of having another heart attack

When patients were asked in the initial interviews about how having a heart attack had affected them, their responses tended to indicate that they were fearful of having another heart attack (especially if fatal), as was discussed in section 4.5.1, and this tended to be associated with anxiety (section 4.5). In contrast, as was discussed in section 6.2.1, in the second interviews patients tended to seem less anxious and none of them talked about being fearful of having another heart attack when asked how things had been for them since the initial interview. They only talked about this when asked if they worried that they might have another heart attack and their responses suggested that they tended to be less fearful about this than they had been, although it seemed that five patients (R4, R7, R10, R11 and R13) still had residual fears. R15 was something of an exception because he seemed to be more anxious than in the initial interview, as discussed in section 6.2.1, and appeared to be fearful about his health in general (particularly that he might have further “mini-strokes”) rather than specifically that he might have another heart attack.

R4, R7 and R10 had seemed particularly fearful of having another heart attack in the initial interview (section 4.5.1) and it was especially striking that these three patients seemed to be considerably less fearful in the second interview. R4 responded to the question about whether he worried that he might have another heart attack by saying, “I do a little”. R10 said that previously “every time you do anything at all it was there in the back of your mind, so you’re quite worried about it” but added “I’ve got past that now”, although his keenness not to “do things that are likely to bring it on” suggested that he had residual fears. R7 said that when he got angina he had “got a bit worried”. He added that since having a stent inserted he had only had “occasional” chest pain, which

had not been severe enough “to worry about” and when asked if he worried that he might have another heart attack he said:

“Well sometimes when I used to get these pains I used to think you know are we going that way again but not so much now.” (R7)

R13 had been worried that he might do something to cause another heart attack (section 4.5.1) but pointed out that the exercise he had done on the CR programme had helped overcome this fear, although later on in the interview he said “it’s in the back of your mind when you get a twinge” of angina. R11 seemed to be a variation on this because in the initial interview he talked about not being fearful of having another heart attack because he was not planning to return to his stressful job (section 4.5.1), which he perceived as one of the main causes of his heart attack (section 4.4.1). When asked in the second interview whether he worried that he might have another heart attack he said “I do think about the future but I don’t worry about it too much” but later on said “maybe it’s a fear of what might happen if I did push myself hard that I daren’t do it” as a reason why he had not been out “road running” on his own since his heart attack. This suggested that he did have residual fears about having another heart attack and also that he may have been more fearful at the time of the initial interview than he said.

R2 and R9 also seemed to be less fearful of having another heart attack than they had in the initial interview but did not explicitly say anything that suggested that they still had residual fears, although this does not necessarily mean that they did not. R2 said that she had been particularly worried when she first went home after her heart attack (section 4.5.1) but reported that she was no longer worried. R9 did not actually talk

about being fearful in the initial interview, although fear could be inferred from what he said about how keen he was to prevent another heart attack. When asked in the second interview whether he worried that he might have another heart attack he said “no, not really no”.

In contrast, R6 had not seemed particularly fearful of having another heart attack in the initial interview (section 4.5.1) and this did not appear to have obviously changed since. When asked whether she worried that she might have another heart attack she said that she did not. R3 did not talk about fear in the initial interview (section 4.5.1) and when asked if she worried that she might have another heart attack said “well no, not really, funnily enough”. She added that she had not been worried after her first heart attack about having another one because “I felt ever so well”.

6.3.3 Assessing risk on the basis of heart damage

It seemed that seven patients had assessed their risk of having another heart attack on the basis of what they had been told about the damage that their heart attack had caused to their heart and/ or what investigations had revealed about how their heart was functioning. This was not something that patients talked about in the initial interviews. The way that these patients talked about this suggested that they did not view themselves to be at imminent risk of having another heart attack, although two patients (R9 and R7) appeared to view themselves to be at longer-term risk. R6 said “I mean the doctor has told me it hasn’t done any permanent damage so I don’t have any negative feelings about it at all really”, whilst R11 and R4 said:

“Well obviously they talked about it. They said that my heart is damaged, permanently damaged but not seriously damaged and I’m cardiologically stable which means I suppose my heart is ticking over ok. I obviously think about the future but...I assume I’ll go on for a while.” (R11)

“They never did find anything as I say in the hospital with all the tests and the twenty-four hour one. Obviously the ultrasound and the erm treadmill and nothing, you know, strange at all. So that as well is at the back of my mind, I think well I’ll just go for it and whatever and get on with things.” (R4)

R3 said that when she had been for “the one where they put the dye in” (i.e. an angiogram) the doctor had told her that “it just looks as though there’s a little bit about that long that’s little bit ragged and that could be, you know, it” (i.e. why she had had a second heart attack within six months of the first) and that “she said I shall have to talk to my colleagues but she said I think you’ll be fine on tablets”. She added “I sat there thinking I’ve been in hospital all that time just for them to tell me I can take some tablets” but shortly after “I thought, you silly fool that means you’re a lot better than what you thought you were” because a procedure, such as an angioplasty, had not been performed. R13 said, “I mean it is worrying; I know one of my three main arteries is blocked” and added that “without an angiogram and really seeing what’s happening” it was more difficult to know how much damage had been done. Since he had not had an angiogram he seemed to have assessed the situation on the basis of other investigations that had been done:

"I suppose it's the just the way you feel and the way results come out, blood tests and ECGs and things and how they show whether things are working or not. So you've just got to take solace from that." (R13)

It seemed that the results from these investigations had indicated that "things" were "working" because he said, "things seemed to have healed themselves and things are functioning ok anyway". R9 said, "I've had an angiogram" and explained that the doctor had told him:

"That's where your heart attack was and that's where you got the pain from but don't worry about that; your heart can compensate without that bit. This [small lesion] is what we'll have to worry about and he just shows me at the junction where it was, yes. Yes he says, we'll have to keep an eye on this for you...he said it isn't bad enough to warrant surgery at this stage. He did say I was probably lucky I had this little bit because now we have found it and if it had been this [gestures a larger lesion] it would have been a bit more severe." (R9)

He added "but how do you keep an eye on something like that without you having an angiogram every six months". This suggested that he viewed himself to be at longer-term risk, which was particularly shown when he said:

"Well at the end of the day I've got to die from something and the chances of it being heart are probably fairly great but you know I accept that at the

end of the day. I was stopped from being popped off last year and I hope I've got another fifteen or twenty years left.” (R9)

R7 said that he had been told that he had only had “half a stent” inserted, which seemed to affect his assessment of his risk of having another heart attack. He explained that this had been compounded by what he had read in a newspaper about the expected longevity of stents, although it seemed that he did not see himself at imminent risk of having another heart attack:

“It’s just that they told me I had only half a stent. Well apparently they’d gone in and they couldn’t get round the corner [of a coronary artery], it was a bend and for some reason they didn’t go round the bend so they only went so far. But they said what they did was doing the job they wanted it to, if you follow what I mean. Instead of forcing it round, rather than trying to do it and cause damage, they left it at that. I mean that was in the back of my mind you know, things like that and then you read in the paper oh it only lasts for five years. Touch wood, I haven’t had it two years yet so I’m alright. [Laughs] I’ve got another three!” (R7)

6.3.4 Risk reduction and personal responsibility

Patients talked about their perceived risk of having another heart attack in terms of their personal responsibility for taking preventative measures, although what they said about this suggested that they tended to think that chance or bad luck might also determine whether or not they actually had another heart attack. This seemed to reflect the changes in their perceptions about the main causes of their heart attack (section 6.3.1),

their assessment of possible damage to their heart (section 6.3.3) and their residual fears that it might happen again (section 6.3.2). When talking about their personal responsibility, patients often referred to taking medicines as well as lifestyle changes as preventative measures they should maintain. R6 and R9 seemed to place particular importance on taking medicines as the mainstay of their personal responsibility. R6 said about her heart attack “I can almost say it is a good thing because it was a wake up call, it was a reminder that I must look after my body if I wish to live any longer, so I don’t really see it as a bad thing” and added:

“I just feel that I don’t have, because I don’t have the obvious erm predisposing factors like obesity, very high cholesterol levels, and family history, because I don’t have those factors I tend to think it was just a bit of bad luck rather than anything else and that as long as I’m taking the medication that claims to look after my heart it’s unlikely that that will happen again. Maybe I’m wrong but I suppose I have settled into that way of thinking.” (R6)

She reinforced this point by saying later in the interview “I do tend to think that the tablets are doing their job and I can just live my life”. R9 said “so you know I just take my pills and wait for something else to happen, like in fifteen years from now you know”. This was because he believed that “eighty-five percent of these problems are hereditary” (section 6.3.1) and was aware of damage to his heart that affected his long-term risk of having another heart attack (section 6.3.3).

Four patients (R3, R10, R11 and R15) seemed to place importance on both medicines and lifestyle changes as preventative measures. R3 said that she thought she would be “jolly unfortunate” if she had another heart attack despite taking medicines and maintaining lifestyle changes:

“I mean I’m afraid I’m a bit sort of well if I try and do things and take the tablets they say and try and do the things I know I should do, which is eat sensibly and do my exercise, it will be jolly unfortunate if I had one you know what I mean. I mean if you’re doing what they say you know.” (R3)

R15 said about job-related stress “I wanted to work but at the same time I didn’t want to expose myself to a similar situation where I had another heart attack”. He also explained that he was trying to be “sensible” about diet because otherwise “you’re just going to put yourself back into the hospital again” and that:

“I think the tablets are being ideal for me really because I’ve now gone a year and a bit and I haven’t had a heart attack so that’s got to be good hasn’t it? I’m sure that the reason is that I’m trying to be sensible where you can and taking medication.” (R15)

Despite these measures, he concluded “what the future will be I frankly don’t know but I’ll just go on and make the best of it”. R10 explained that as long as he “acted in a reasonable manner” and took the medication, “if it’s going to happen it will happen” and that “there’s not a great deal more you can do”, although he added that “perhaps smoking doesn’t help”:

"I have to stop doing stupid things like trying to lift ten tonne weights you know or working myself into the ground but I do think at odd times you know am I going to have another one, what caused that one, could it happen again anyway because I haven't a clue what brought it on, you know. As far as I can see I hadn't done anything in particular that day you know so if it's going to happen it's going to happen, there isn't much I can do about it other than not be stupid and do things that are likely to bring it on. Perhaps smoking doesn't help but you know any overexertion or pushing myself beyond what I feel is the limit you know...you just act in a reasonable manner and hopefully it won't happen again. Take the medication and there's not a great deal more you can do, you've just got to get on with your life and carry on." (R10)

Apart from the issue of personal responsibility, suggesting that "overexertion" might cause another heart attack seemed to reflect a departure from the advice given on the CR programme about strenuous physical exercise being desirable. This same idea appeared to also be expressed by R11, who talked about "taking the medication" and "behaving normally":

"I obviously think about the future I suppose but you don't know what could happen do you. As far as I keep taking the medication I suppose and I act you know, behave fairly normally I assume I'll go on for a while you know [laughs]...I mean I do think of the future a bit but I don't worry about it too much; what's going to happen will happen." (R11)

When asked what he meant by “behaving normally” he said “sort of normal you know, the things I do; no mountain climbing or anything like that or parachuting or scuba diving”. He explained that he did not do quite as much strenuous exercise as he had done prior to having a heart attack (especially “road running”) because of “what might happen if I did push myself hard” (as discussed in section 6.3.2). In addition, he said about his heart attack that “perhaps it was a warning to slow down” and talked about his risk of having another one being increased if he went back to work:

“And then there’s this thing, the fact that if I did go back to work it could obviously recur, the pressure would be build again and it would be like it was before.” (R11)

R4 seemed to place particular importance on maintaining lifestyle changes (especially doing regular physical exercise) when talking about personal responsibility for taking preventative measures. When asked if he worried that he might have another heart attack he said:

“I do a little and then that’s really what’s in the back of my mind with the gym and keeping as active as possible and you know keeping my weight right. Doing as much as I can in other words so that if it was to happen I would have as good a chance as possible again but as I say when I go to the gym and I work as hard as anybody and just feel fine it sets my mind at rest really. They never did find anything as I say in the hospital with all the tests. So that as well is at the back of my mind, I think well I’ll just go for it and whatever and get on with things.” (R4)

In contrast, whilst the other three patients (R2, R7 and R13) talked about personal responsibility for taking preventative measures, they did not explicitly talk about chance or bad luck. R2 pointed out that she had not started smoking again and that her “cholesterol’s nicely down”, whilst R7 said that in relation to his diet he had “tried to cut a lot of stuff out” and that he did “exercise a bit; before I didn’t do any walking anywhere”. He added that his heart attack had been “a wake up call you know” to make these changes to his lifestyle. R13 said “people sort of feel full of you know what might happen and what might not and so forth” and added “if anything I think I’m healthier”, which was mainly because he had “followed an exercise regime since I left the rehab programme...so there’s a lot of exercise being done”.

6.4 Perspectives on risk reduction and lifestyle modification

Table three summarises the lifestyle changes that patients said that they had made by the time of the initial interview, as discussed in section 5.2, and the lifestyle changes that they said they were still maintaining or had made by the time of the second interview. These changes are indicated by a tick, whilst a cross indicates a perceived lifestyle cause that had not been initially changed or that had been initially changed but not maintained and a question mark indicates uncertainty over whether changes had been made or maintained. An asterisk indicates an aspect of lifestyle that had not been cited by the patient as a perceived cause of their heart attack.

Table 3

Patient	Initial lifestyle changes				Changes maintained or initiated			
	Smoking	Exercise	Diet	Stress	Smoking	Exercise	Diet	Stress
R2	✓	✓	✓		✓	✗	✗	
R3		✓*	✓*			✗	✗	
R4		✓*	✓*			✓*	✓*	
R6		✓		?		✗		✓
R7			?			✓*	✓*	
R9							✓*	
R10	✓				✗			
R11			✓	✓			✓	✓
R13		✓*	✓*			✓*	✓*	
R15		✓	✓	✓		✗	✓	✓

As can be seen from table three, five patients (R2, R3, R6, R10 and R15) did not seem to have maintained all of the lifestyle changes that they had initially made, whereas three patients (R4, R11 and R13) did seem to have maintained all of their lifestyle changes. The five patients who did not seem to have maintained all of their initial lifestyle changes talked about the difficulty they had had in trying to maintain the changes (R2, R3, R6, R15) or the negative effects that the changes had had on their quality of life (R10). It also seemed that these patients now placed less value on maintaining these changes for the purpose of preventing another heart attack, at least in part, because they viewed these aspects of their lifestyle as being less likely causes of their heart attack than they had previously done. This appeared to have resulted from the changes in their perceptions about the main causes of their heart attack (section

6.3.1) and their perspectives on their personal responsibility for preventing another heart attack (section 6.3.4). R3 appeared to be an exception to this because she did not talk about the likely causes of her heart attack in the initial interview and it was not clear whether there had been any change in the value that she placed on maintaining lifestyle changes. There did seem to have been a change in how she conceptualised lifestyle change compared to the initial interview, although it was not clear how much this was related to her perception of risk, since in the initial interview she had not seemed particularly keen to do regular physical exercise (section 5.2.2) and being overweight appeared to have been a longstanding issue (as is discussed later in this section). In contrast, the three patients who seemed to have maintained their initial lifestyle changes talked about the benefits they had experienced as a result and where there appeared to have been changes in their perspectives on the main causes of their heart attack (section 6.3.1), this did not seem to have affected the value that they placed on maintaining these changes as preventative measures. R7 and R9 did not talk about lifestyle changes they had made in the initial interview (as discussed in section 5.2) so comparison could not be made, although what they said about the lifestyle changes that they had made appeared to reflect their perspectives on the causes of their heart attack and their risk of having another.

Of the patients who had not maintained all of their initial lifestyle changes, R6 talked about having reduced her job-related stress but had not maintained the regular physical exercise she had previously been doing. At the time of the initial interview doing regular physical exercise had been the main lifestyle change she had made (section 5.2.3) since she had not viewed her diet as being a problem (section 5.2.2), which was a view she continued to hold:

“My diet on the whole is good, I mean I do like things that are good for me...Most of the time, I mean during the week particularly when I am at work erm in the winter I have a dinner that’s mostly cooked vegetables, in the summer it’s mostly salads and fruit. If I’m going to have a cream cake or a pizza it would be only at a weekend and it wouldn’t be every weekend, it would only be an occasional thing.” (R6)

She did not talk about reducing job-related stress in the initial interview (section 5.2.4) but did talk about this in the second interview. She said “I realise that erm it’s not a question of stress and no stress, it’s a question of accepting that stress is a part of life and learning how to deal with it”. The changes that had made to reduce her stress included patients having to come to see her, rather than her having to travel to see them and that more training courses had been arranged locally, which avoided the “stress of long journeys and very early mornings”. On the subject of exercise she said:

“Erm I’m lazy and unreliable when it comes to things like exercise. I mean when I met you last year I was doing it religiously. I was fit as a bean and erm doing exercises every other day and all the rest of it. Now that’s gone by the wayside a bit, I exercise now and again when I feel like it and I know that that’s unwise, I know I should do it more regularly. I do however walk to work everyday and back and I never used to do that before because I was working out of town I drove everywhere. So at least I’ve got a little bit of very, very basic exercise; it’s not demanding in any way but the actual more demanding exercises when you actually, you know, take

an hour out of your day and you make a point of working up a bit of a sweat you know, that I do much less than I used to.” (R6)

When asked why she did less exercise she said: “it’s just because I’m lazy, you know I think oh I can’t be bothered”, although it also seemed that she now placed less value on doing regular physical exercise as a preventative measure than she had previously done. This was because she now thought the main cause of her heart attack was “a bit of bad luck rather than anything else” (section 6.3.1), such as lack of exercise as she had said in the initial interview (section 4.4.2), and that she talked about taking medicines as the main preventative measure she needed to continue to take (section 6.3.4). Subsequently, it seemed that she now viewed doing regular physical exercise as just being generally “good for anybody and everybody”, rather than being something that had particular relevance for her:

“I probably can live with myself because I’m a bit lazy but erm I do tend to feel that taking the tablets regularly is going to ensure that my body is looked after properly, erm although I know that regular exercise is good for anybody and everybody really. It’s not just for the health of the heart in people who have had a problem but heart health for everybody.” (R6)

The only lifestyle change that R10 had made by the time of the initial interview was to stop smoking (section 5.2.1) but because of the negative impact that this had had on his quality of life he had subsequently started smoking again after eight weeks:

"I gave up smoking, or at least I tried...you know I decided it wasn't for me...I was, you know, wanting a cigarette all the time. You know, depressed, I decided it wasn't right...I just sort of felt miserable all the time." (R10)

He did not seem to have thought that his diet was a likely cause of his heart attack (section 4.4.2) and had not changed his diet. Similar to what he said in the initial interview (section 5.2.2), he said that this was because he "wasn't eating too many fatty foods or having pavlovas, or banoffee pies and things like that" and emphasised this point by saying:

"I don't eat a lot of fatty type foods anyway, I have the occasional chocolate but we don't cook with animal fat because my wife is vegetarian anyway. I have meat and I love Yorkshire puddings and roast potatoes and vegetables but not cooked in dripping or lard or anything like that. I don't think I've ever eaten McDonalds. Me, I don't like burgers full stop, McDonalds or anybody else's you know I like proper meat." (R10)

It did not seem that he was doing any more regular physical exercise than he had done before he had his heart attack. This included walking his dogs every day and going "out quite a bit in the summer on the bike" whilst wearing "one of those monitor things like they had at the rehab" so that he could "be sure I'm not overdoing it". In the initial interview he talked about intending to do more exercise such as joining a gym but when asked about this in the second interview he said:

“I seriously considered it but then when you start to look at the cost, it’s not cheap you see. I know it doesn’t look all that expensive I don’t suppose but when you think how it will add up bearing in mind that you know I’m on a works pension, I don’t get my old age pension anyway. I’ve got to live on that, there isn’t all that amount of money available.” (R10)

He had seemed even more uncertain about what had caused his heart attack than he had done in the initial interview and talked about not having “done anything” to “bring it on”, rather than smoking being a likely cause (section 6.3.1). He talked about chance being a major determinant in whether he had another heart attack when he said “if it’s going to happen, it’s going to happen, there isn’t much I can do about it” and it seemed that he mainly saw prevention of another heart attack as avoiding “overexertion” and taking medicines (section 6.3.4). This is what he appeared to mean by “acting in a reasonable manner” and saying that “perhaps smoking doesn’t help” suggested that he may have placed less value on stopping smoking as a preventative measure than he had previously done.

R2 talked about having not started smoking again but it appeared that she was doing less, if indeed any, regular physical exercise than at the time of the initial interview. She said (about exercise) that as a result of attending the CR programme “you just get yourself sort of a little bit motivated and it does help you and then you don’t do it anymore”, largely because she had finished attending the programme. She had been overweight at the time of the initial interview and by the time of the second interview seemed to have put on more weight. Although she had agreed to her Consultant’s request to go on a diet, she said that it was “so damn difficult” because she had been

told to “cut out lots of things” and particularly that she was only “allowed a matchbox-size piece of cheddar about once a week”, which suggested that she was less than keen. She explained her weight gain by saying “you’ll be surprised where all the hidden fats are, in gravy and whatever” and remarking about how many calories there are in “a bit of Christmas pudding” or “a few mince pies”, implying that this had unexpectedly contributed to her weight gain because she had not been “going mad”. She also blamed the impact of being on holiday and temporary restriction of movement due to cellulitis:

“We’d been on a cruise and then about a month later I got another episode in my leg [of cellulitis] and I thought you can’t sort of sit and not eat anything!”(R2)

Compared to the initial interview, she now seemed to consider that smoking and her raised cholesterol had been more likely causes of her heart attack than being overweight and not doing enough physical exercise (section 6.3.1). This suggested that she now placed less value on doing regular physical exercise and dietary change as preventative measures than she had previously done, particularly since she pointed out that she had not started smoking again and that her “cholesterol’s nicely down” when talking about preventing another heart attack (section 6.3.4).

R15 talked about the dietary changes he had made and how he had tried to reduce his job-related stress but it seemed that he was doing less physical exercise than he had previously been doing. He said “I think I put on a little bit of weight which I’ve not been able to get off” but said about his diet:

"I do try to be careful on the problem of diet. I have a good appetite and I steer away from fatty foods and fried food. I've read all the books and leaflets and information that was given to me and I'm trying to be sensible...The only thing that I find hard is that there are two things that I've never liked in life are the things that I should be having more of which is fruit. But I do try to eat vegetables and obviously we've cut down on fatty foods, if we have chips we have the oven chips. And we have tried to eat sensibly; we grill everything, cut all the fat off things. If we have bacon we have lean bacon." (R15)

As he had done in the initial interview (section 5.2.4) he talked at length about his job-related stress and how he had tried to reduce it:

"I wanted to work but at the same time I didn't want to expose myself to a similar situation where I had another heart attack...and I think I carried on quite well, really I tried to...I carried my spray, I tried to avoid heavy lifting or stressful situations if I could and I felt I'd got it under control...I had one or two situations where I just felt completely washed out and tired but I kept going and kept going." (R15)

However, it seemed that this had only had a limited effect since he still found the job stressful. He talked about doing less exercise than he had previously been doing and said that although he had "tried to do a little bit more cycling and walking", he had found it hard because "it's a discipline". He added "if you've had a bad day at work and you feel tired you really just want to do what you have to do without taking on extra walks

and cycling". As discussed in section 6.3.1 he seemed to think that job-related stress had been the main cause of his heart attack as well as wondering whether he had been "eating the wrong stuff" but did not mention lack of exercise as he had done in the initial interview (section 4.4.2). He also did not mention doing regular physical exercise when talking about preventing another heart attack (section 6.3.4), which suggested that he now placed less value on physical exercise as a preventative measure than he had previously done.

R3 did not seem to have maintained any of the lifestyle changes that she said she had initially made. She had been overweight at the time of the initial interview but said she was "trying to eat just a little bit less" (section 5.2.2). In the second interview she did not appear to have lost any weight and if anything had gained more, which she explained:

"I mean I know I'm overweight and I know I should get more off but that's easier said than done because I've always been overweight, I think I was overweight at eight years old, if you see what I mean. They didn't notice things like that then, not in my age group anyway. It wasn't because we ate all that well because we didn't. It was fat bacon that we had and steam puddings [laughs], no that wouldn't help, and my mum always said she could get fresh cows milk but I was sick ever so much if I had it so she tended to bring me up on Libby's tinned milk you know evaporated milk, diluted. Well I think that would be giving me a lovely start wouldn't it, put the ounces on. But she's still alive and I can't turn round to her and say you would have done that on me wouldn't you because you think I'm on the thin side, you know what I mean." (R3)

She had not seemed very keen to do regular physical exercise in the initial interview (section 5.2.3) and when asked if she was still doing as much exercise as she had previously been doing she said:

“No less I think. Less in a sense if they don’t call using an electric sweeper and going up the stairs and down again sort of thing and hanging clothes out. Then there’s getting the vegetables out of the garden and you know bringing them in and that sort of thing. It’s not that I’m sitting here doing nothing because I’m not, while you’re doing that you’re moving about aren’t you. I feel that it is but as I say my husband wants me to be fit and doing so many jumps up and down and other things, which I don’t and then I sort of think it’s got to the end of the day and I think I really haven’t done anything today. Oh but then you have done so and so and so and so you know. Like today you see, I walked into the village and you think well there are three shops that way and then there’s the library and the bank across the other side of the road and coming further in there’s the butchers, so it isn’t just going there and back again.” (R3)

Her idea of what doing “exercises” meant seemed to have changed from the initial interview (section 5.2.3) in that she now thought that everyday activities constituted “exercises”, rather than the physical exercise she had done on the CR programme and this seemed to be a source of tension between her and her husband. As discussed in section 6.3.4, she seemed to place value on “eating sensibly” and doing “exercises” as preventative measures but her idea of “doing what they say” appeared to have changed.

In contrast, R4, R11 and R13 seemed to have maintained the lifestyle changes that they said they had made by the time of the initial interview and talked about the benefits they had experienced as a result. R4 said “I watch, really do watch what I eat” and about exercise said “I’m still going to the gym and it’s just great”. In the initial interview he had talked about wanting to get “exercise on prescription” from his GP (section 5.2.3), which he had subsequently done and said “you know it really paid off”. He said about the exercise he had done on the CR programme “I did feel a difference when I was going there and I looked forward to it and I enjoyed it”. He pointed out that he now exercised regularly at the gym and was “as fit as a butchers dog”. As discussed in section 6.3.1 he still could not explain why he had had a heart attack other than it being a matter of chance but still seemed keen to maintain the lifestyle changes he had made. R13 said that as a result of the changes he had made to his diet “we don’t really have a bad diet, we don’t eat fat stuff” and that he now followed an “exercise regime”:

“I’ve followed an exercise regime since I left the rehab programme and I do cardiovascular sort of running exercises and walking, I tend to walk quite a lot and I do tend to walk fairly quickly so there’s a lot of exercise being done.” (R13)

He pointed out that he enjoyed doing physical exercise and that as a result thought he was “healthier”. He too could still not explain why he had had a heart attack, although he now thought heredity was a more likely cause (section 6.3.1), but still seemed keen to maintain the lifestyle changes he had made. R11 had taken early retirement from work as a measure to reduce job-related stress and said “now I’m more relaxed”. He also said “I have changed my diet quite a bit” to reduce his cholesterol and pointed out

that only “occasionally we have a treat”. These lifestyle changes related to his perception of the likely causes of his heart attack, which did not seem to have changed by the time of the second interview (section 6.3.1). As far as regular physical exercise was concerned he said “I get some exercise” and talked about cycling regularly and that he went out for a walk “most days”, although he said that he did not do quite as much strenuous exercise as he had done prior to having a heart attack, particularly “road running” (as discussed in section 6.3.2).

R7 and R9 did not talk about lifestyle changes they had made in the initial interview but were asked in the second interview whether they had made any changes to their lifestyles. R7 remained uncertain about what had caused his heart attack but talked about aspects of his lifestyle that may have contributed to it (section 6.3.1). He said that subsequently he had lost “over a stone” in weight as a result of being on an “enforced salad diet” and that he had “cut a lot of stuff out” such as “chocolate, fish and chips, fry ups you know”. He had also joined an informal group from the next village who met regularly to go for walks, despite his difficulty keeping up and going as far as the others because he used crutches as a result of a long-standing problem with his back (see table 1, section 4.2). On the other hand, R9 thought that heredity had been the main cause of his heart attack and that his lifestyle had only made a minor contribution (section 6.3.1). He emphasised this point by saying that he had been brought up on a farm and had a “good, balanced diet” and that he had “never seen the inside of a McDonald’s, so to speak”. As a result he said about his diet “I have changed it a little bit but not much” because “this five fruit and veg a day I’ve always had that anyway”. He also said that he had always had an “active lifestyle” and had not been able to “discipline” himself to do regular physical exercises as he had on the CR programme.

6.5 Perspectives on risk reduction and taking medicines

6.5.1 Continuing to take the medicines

All of the patients indicated that they were still taking the medicines that they had been prescribed after their heart attack and talked about having no intention to deliberately stop taking them, although five patients (R4, R6, R9, R11 and R13) talked about having forgotten to take doses on occasions. It seemed that patients still tended to employ a strategy to help them to remember to take their medicines, as they had done at the time of the initial interview. R3 said “I have a routine going you see”, explained which medicines she took at which time of time of day and added “so I’ve got it sorted out”. R10 said that he did not forget to take his medicines because “I’ve got one of those pill organisers”. R2, R7 and R15 similarly talked about having a routine to help them remember to take their medicines. As a typical example of how these patients responded to the question about whether they had thought about not taking their medicines, R7 said:

“Well as far as I’m concerned wotsit [label on medicines] says don’t stop them unless your doctor says so, I mean [consultant cardiologist] has told my doctor or he’s going to tell him what tablets I’m on and how much to keep me on...As far as I’m concerned they’ve told me to take them and I’ll take them until they tell me not to.” (R7)

R4 said “I always take them” and explained that “if I do forget, I’ve actually got to work in the morning and thought oh blast I’ve not had my tablets and I’ve just nipped home again and taken them”, since he lived close to his workplace. He added “I do try to take them at the same time everyday and yes I do want to alter them but I only want to do it

through my GP so he knows what's happening", rather than just deciding not to take them (his desire to "alter" his medicines is discussed in more detail later on in this subsection). R11 said "no I never forget no, no" and described his routine to ensure that he did not forget them but added:

"I know one or two occasions I have forgotten the ones in the evening and realised perhaps eight, nine o'clock at night I hadn't taken the evening two and I've taken them then but I've never not taken them." (R11)

R6 explained that she had decided to take her statin in the morning rather than the evening because she found it easier to remember to take it:

"I've even changed my statin so that I can take it in the morning with all my other tablets because I used to take the statin at night and you know I would sometimes forget or I'd sometimes take them late whereas taking them all in the morning it's become as much as part of my routine as cleaning my teeth so I just don't give it much thought. Automatically first thing in the morning, husband brings me in a cup of tea in bed I get my little pot, get out my tablets swig them down and I barely even think about it." (R6)

R13 said "I can't say I haven't forgotten the odd pill but it is the odd one" and explained that it was the medicines that he took in the evening that he was most likely to forget. He said that he did not forget to take the "bulk" of his tablets because "it's part of the breakfast routine and they're in my face when you go through into the room" but "the

nine o'clock ones" were the medicines that he had forgotten "two or three times over a year". He said "I wouldn't not take them" and pointed out that:

"They warn you not to stop them anyway for any reason, the odd one obviously you might miss but you know you shouldn't just give up taking them pills." (R13)

R9 said "well I miss one day a week probably because I have too much on my mind you see". He explained "what happens is you have a routine, we all have a routine but if something breaks your routine" then he was more likely to forget to take them. Unlike R6 and R13, he said that "it's the ones in the morning" rather than the medicines he took in the evening that he was more likely to forget because "you know if I suddenly I get someone ring or something like that". This had meant that "occasionally, probably no more than once a week or once every ten days I go to pot with it." When asked if he had thought about not taking the medicines at all he said "I've not given that any thought at all, no".

Even though all of the patients appeared to still be taking the medicines that they had been prescribed following their heart attack, five patients expressed a sense of disquiet about taking them. This was expressed by three patients (R2, R4 and R9) in relation to the side effects of their medicines, by one patient (R3) in terms of ideally preferring not to have to take medicines and by one patient (R15) in both ways. R2 in particular had a lot to say about the side effects of the medicines she was taking, especially about the cough she had experienced when taking ramipril before it had been changed to losartan (sections 5.3.1 and 5.3.2). She explained that:

"When I changed the tablets over from ramipril to losartan, oh it took me a long time to get used to them and I didn't feel particularly well on them, I didn't feel as well on them as I did on ramipril. I couldn't really explain it, not very well in myself. It was a question of energy, I'd get up feeling urgh I don't feel very good today...they don't really like changing our medicines do they. Once they get you settled on something and perhaps it's true to say that coz ramipril is tried and true, I mean the fact that it's cheaper I think is irrelevant, it's tried and true and I think it works and I don't know about losartan whether it does or not. I don't cough as much but was it as effective as the ramipril?" (R2)

She pointed out that the cough "goes but and then you could go probably a few days and not cough and then you might have a day when you are coughing on and off all day and also you do have a sniffy nose with it". She added "I bruise more easily coz that's the aspirin" and that she thought that her medicines were responsible for making her "skin sensitive, makes it itch I don't know but sort of dry, little dry patches of skin". As a result if this she seemed to have remained keen to know about the potential side effects of her medicines:

"Unless you're aware of your side effects, I don't know. I don't think many people are, I don't know whether they don't read about them but I do. So I know what they're supposed to do." (R2)

R9 expressed disquiet about his medicines because he had experienced side effects. He said “they took me off aspirin because I was getting gut problems” and had prescribed clopidogrel instead. He also said:

“They [medicines] messed my bowel motions up as well, which I think is fairly common sort of thing. From flatulence to blowing up like a balloon yes! [Laughs] I put up with that you know to still be here.” (R9)

He also expressed a similar sense of disquiet about the potential for his medicines to cause further side effects:

“But I do think with all these tablets I take now, I mean six in the morning and five at night, and I do wonder when I’m popping these down what the bloody hell they’re doing but anyway. But as the specialist said well you’re still alive and they’re not going to do you any harm so if they make you live longer.” (R9)

R4 seemed to express the most disquiet about his medicines, which appeared to have resulted from the problems he had had, as discussed in section 5.3.1. A particular concern was the “discomfort” he had been getting, which he had eventually been told was “all to do with the indigestion” rather than angina (as discussed in section 6.2.1). He explained that subsequently “tablets started that way” and he had not experienced the “discomfort” since. This seemed to have caused him to question whether certain heart-related medicines that had been started or had doses increased to deal with this “discomfort” were necessary because they had not relieved his “discomfort” and may

even have made it worse. As a result of this he said that he had “badgered” his GP to reduce these medicines and his doctor had subsequently reduced his isosorbide mononitrate dose by “a third”.

“I still badger him to alter, to take the tablets down the other way now to reduce them, we have reduced the Monomax [isosorbide mononitrate]. I always had a feeling, well I told him that it did make this ache and what have you worse and said I don’t understand why but it definitely is the case but I think before all these other things were going on before we got the results of the endoscopy and you know before I was going to the gym, he thought that it was still an angina type pain so I can’t remember the last time I used the [GTN] spray. I could never, I struggle to understand as I never had angina or I don’t believe I ever had angina before I had the heart attack why should I have it after, nobody’s explained it to me...But this particular tablet kept going up and going up because of the ache but now he reduced it by a third the last time I saw him and I shall see him again shortly in and ask him you know because I want to give it a go and you know if I do get some angina type pain then I’ll tell him and go back on it. It’s probably just me, I just don’t like the thought of being on seven tablets for the rest of my life.” (R4)

When asked further about why he did not want to be on “seven tablets” for the rest of his life he explained that this was because he did not want to take medicines that he did not “need to take”, as well as that he remained concerned about experiencing side effects:

"I don't want to just take tablets if I don't one hundred per cent need to. No I'm not happy taking something I don't need to take. I'll take the ones that are doing me good but you know the losartan, I would like to know whether I do necessarily need it. I think it's the side effects thing as well in the back of my mind to be honest that I think well I would certainly rather not have the chance of having any of those side effects if possible but even with the aspirin if I thought one aspirin a day would suffice." (R4)

He added that his concern about side effects had been partly caused by the information that he had been given that just listed that "this drug can cause baldness you know, impotency, aches, coughs, wheezes, ticks, all sorts of things", rather than giving an indication of how common any of the side effects were. This was very similar to what he had said about medicines-related information in the initial interview (section 5.3.2).

R15 said that "I just feel until dinnertime absolutely lousy" and that "I feel as though I've been heavily drinking the night before", which the doctor had told him "that's par for the course for the tablets that I've been given you and you know you'll come round and adjust to that". He pointed out that "I don't think it's to do with the heart tablets because I've never felt just like that with taking the tablets for the heart" and instead attributed this effect to "the drug he's given me to sort of ease the mind a little bit". It seemed that his disquiet about medicines was mainly concerned with the medicine he had been given to "ease the mind" because he said "I was a bit dubious about taking these tablets", since he "didn't want to become dependent on them" like some of his friends who were "on heavy medication to get them through", although he added that in general "I'd sooner not take any tablets of course but life's not like that is it". This seemed to be

similar to what R3 said, who commented that “it’d be nice if I didn’t have to take them” but explained that because she was “one of these people you see if I had a headache I’d take a couple of Anadin” and so “I’m very much you know, if they think you need them then you need them you know”.

In contrast five patients (R6, R7, R10, R11 and R13) did not appear to express any disquiet about taking medicines. Indeed, when asked if she had considered not taking the medicines R6 explained that she was quite happy to take them:

“I have a lot of patients myself who are desperate to stop taking medication. They think they can’t take this indefinitely, I’ve got to stop, it’s not natural. They have thing, they’re supposing that somehow the medication is compromising their body’s natural way of living its life, whereas I feel that perhaps the tablets are complementing my life and therefore maintaining it at this level of health. I feel that I’m more likely to suffer if I stop taking them.” (R6)

6.5.2 Explaining how the medicines reduce the risk of further heart attacks

As discussed in section 5.3.3, in the initial interviews patients did not seem to relate how they thought the medicines reduced their risk of having another heart attack to the perceived causes of their heart attack. In the second interviews it seemed that patients tended to remain uncertain about how the medicines reduced their risk and whether this related to the cause of their heart attack. Four patients (R2, R3, R4 and R9) talked about how they thought the medicines reduced their risk, whereas two patients (R6 and R7) talked about trusting health professionals’ opinion that the medicines would reduce

their risk, rather than offering their own explanations and four patients (R10, R11, R13 and R15) did not say anything about how they thought the medicines reduced their risk.

Of the four patients who talked about how they thought the medicines reduced their risk, R4 talked about the medicines having reduced his blood pressure and cholesterol, although as discussed in section 6.3.1 he remained uncertain about the causes of his heart attack:

“They’ve worked you know, I’m still here so you know they must be, they’ve got my blood pressure down and got my cholesterol down so they must be working. The aspirin, you read about all the time that it’s a marvellous thing.” (R4)

When talking about medicines R2 said “cholesterol’s nicely down, it’s down to about four”, which seemed to relate to her perception that high cholesterol had been a cause of her heart attack (section 6.3.1). She also pointed out that her “blood pressure is er a hundred over about seventy”, although she had not cited high blood pressure as a cause. R15 also said that the medicines had reduced his blood pressure, although he too had not cited high blood pressure as a cause of his heart attack. Similarly, R3 did not seem to relate how she thought that the medicines reduced her risk to the causes of her heart attack when she said that “one was thinning the blood and one was something to do with it, to keep me going”. R9 talked about the medicines reducing his blood pressure and cholesterol to “keep everything singing and dancing” but it seemed that he was uncertain about how much effect the medicines may have on his risk because he thought that heredity had been the main cause of his heart attack (section

6.3.1) and the medicines would not make the lesion in his coronary artery (section 6.3.3) “better”:

“I take one for blood pressure I’ve been taking that for years and we know that one keeps my cholesterol down and that’s good for the heart so that’s important and one to keep it on the right beating and all the other blooming things, they’re all there for a purpose because I’ve got a problem...I’m on the tablets to keep everything singing and dancing but I realise at the end of the day it’ll not get better.” (R9)

Of the two patients who talked about trusting health professionals’ opinion that the medicines would reduce their risk, as opposed to giving their own explanations, R7 compared his approach towards medicines to patients who knew “exactly what they were for, side effects and everything” by saying:

“If someone says take an aspirin I take an aspirin. As far as I’m concerned he’s the doctor and he knows what they are for...the way I look at it they’re the blokes that have done the five years training, I haven’t. There’s a lot of training gone in to what they’re doing and they’re qualified to do it...My doctor is pretty good, he does occasionally go through my tablets and say you’re still taking all these aren’t you? Sometimes he’ll say do you really need that? I answer him I don’t know what it’s for, because I don’t...I mean I know four of them are for my heart but what they do don’t ask me coz I don’t know and that’s what I tell him. As far as I’m concerned he’s the bloke, he knows what they’re supposed to do.” (R7)

R6 explained that her GP had started her on an ACE inhibitor as well as a beta-blocker, which her consultant had appeared to agree with (c.f. sections 5.3.2 and 5.3.3). She pointed out “I suppose I’ve no way of knowing whether my body is no longer using this medication and doing its job without them” but that her GP had said that “all was well because of the level of medication and therefore to stick with that level”. She also said:

“I’ve read what they do to my body and I assume that the people that wrote that know what they are talking about and therefore that’s what’s happening. So I’m completely confident that the medicines are looking after my heart.” (R6)

6.6 Chapter summary

The impact of having a heart attack appeared to be considerably less for seven patients, whereas the other three patients’ lives seemed to still be significantly affected. Nine of the patients now saw their GP infrequently, which seemed to confirm their own perceptions of their health having improved. Patients had had little, if any, contact with other health professionals or heart-related health services and none had joined a CHD patient group.

There tended to have been subtle changes in patients’ views on the causes of their heart attack, although uncertainty about the likely causes remained. Patients tended to be less fearful of having another heart attack, although residual fears often appeared to remain. Patients tended to have assessed their risk of having another heart attack on the basis of damage done to their heart but did not appear to view themselves to be at imminent risk. All of the patients talked about their personal responsibility (in terms of

taking medicines, lifestyle changes or both) for preventing another heart attack, although they often referred to chance or bad luck determining whether it actually happened.

Five patients justified not having maintained all of their lifestyle changes but appeared to now place less value on maintaining these changes, at least in part, because they viewed these aspects of lifestyle as being less likely causes of their heart attack than previously. Three patients who had maintained their lifestyle changes talked about experiencing benefits and the value that they placed on maintaining these changes did not seem to have changed.

All of the patients indicated that they were still taking their medicines and, when asked, talked about having no intention to deliberately stop taking them, although five patients mentioned forgetting doses on occasions. Despite this, five patients expressed a sense of disquiet about taking medicines, either in relation to side effects or in terms of ideally preferring not to have to take them. It seemed that patients tended to remain uncertain about how the medicines reduced their risk and whether this related to the cause of their heart attack. In the next chapter the analysis of the data from the interviews with CR patients who had not had a heart attack is discussed and comparisons are made between their perspectives and those of the heart attack patients that have been presented in this and the previous two chapters.

Chapter Seven

Analysis of interviews with CR patients who had not had a heart attack

7.1 Introduction

The aim of the third stage of the study, as discussed in section 3.3.1, was to conduct in-depth qualitative interviews with CR patients who had not had a heart attack in order to explore their perspectives on CHD and treatment, so that these could be compared with the perspectives of the CR patients who had had a heart attack. This was because there appeared to be three issues that emerged from the interviews with R16, which when considered together suggested that his perspectives on CHD and its treatment may have been different to the heart attack patients (including R8 who had a CABG after having a heart attack) and that this may have been because he had not had a heart attack. Firstly, he talked about his risk of having a serious CHD-related event (i.e. heart attack or death) being a matter of bad luck or chance and said that he was not worried about it. Secondly, whilst he thought that smoking was a likely cause of his CHD, he had stopped smoking twenty-five years ago. He did not seem to think that any other aspects of his lifestyle had been likely causes and subsequently did not seem to have maintained lifestyle changes that he made around the time of attending CR. Thirdly, he talked about his medicines being prescribed to control his angina, rather than to reduce the risk of serious CHD-related events. In addition, his perspectives on risk did not seem to have changed by the time of the second interview, whereas the heart attack patients' perspectives on this did tend to have subtly changed (section 6.3.1).

In practice, as discussed in section 3.3.3, the CR patients who had not had a heart attack were those who had been referred for CR because they had had CABG surgery. R16 (who was excluded from the initial and second stages of the study because he had not had a heart attack) was included in this sample of patients, as discussed in section 3.3.3, to give a total of thirteen patients who had not had a heart attack but had undergone CABG surgery. The aim of this chapter is to discuss the analysis of the data from the in-depth interviews that concern these thirteen CR patients' perspectives on CHD and treatment.

Demographic information about the patients is included in section 7.2 and their experiences of having CABG surgery are discussed in section 7.3. Their perspectives on the risk of experiencing a serious CHD-related event is discussed in section 7.4. Their perspectives on lifestyle modification are considered in section 7.5 and their perspectives on taking medicines are discussed in section 7.6. Key points are summarised in the final section of the chapter.

7.2 Patient demographics

Demographic information about the patients is summarised in table four. Patients' descriptions of their other medical conditions were used, as specific medical diagnoses were not known in many cases. All of the patients were Caucasian. Eleven patients were married and living with their partner, whilst two patients were not living with a partner and none of the patients were related.

Table 4

Patient	Age	Sex	Occupation	Other Medical Conditions
R16	70	M	Retired laboratory technician	Angina for fifteen years, high cholesterol,
R17	76	M	Retired: former occupation unknown	Angina for ten years
R18	72	M	Retired civil engineer	None reported
R19	63	M	Security guard on sick leave	None reported
R20	76	M	Retired fireman	None reported
R21	72	F	Retired: former occupation unknown	High blood pressure
R22	69	M	Recently retired lorry driver	Diabetes
R23	79	M	Retired: former occupation unknown	High blood pressure, prostate problem, arthritis
R24	72	M	Retired: former occupation unknown	High blood pressure
R25	77	M	Retired: former occupation unknown	High blood pressure, under-active thyroid.
R26	65	M	Recently retired shop manager	Diabetes, high blood pressure, gout
R27	69	M	Retired office-based worker	Angina for nineteen years, high cholesterol
R28	57	M	Retired from Armed Forces and not currently working	Arthritis, diabetes, asthma

Table 5

	Time period between CABG surgery and interview (months)		
	10-12	13-24	25-27
Number of patients (n=12, i.e. excludes R16)	3	5	4

7.3 The experience of having coronary artery bypass surgery

7.3.1 Interpreting the symptoms and seeking medical care

At the beginning of the interview patients were asked about the events that had led to them having CABG surgery. Patients tended to respond to this question by talking about the symptoms that they had experienced, how these had been initially interpreted and what had prompted them to go to see their GP. Conversely, patients tended to say little about the sequence of events that resulted from seeing their GP, which led to them having CABG surgery.

All of the patients reported that the symptoms they had experienced had been chest pain, shortness of breath or both. Typically these symptoms occurred over a longer period of time and did not seem to have been associated with the same degree of fear and distress that the heart attack patients tended to experience. Seven patients (R17, R18, R19, R20, R21, R27 and R28) said that they had initially attributed their symptoms to non-cardiac causes, which was similar to the experiences of the heart attack patients (section 4.3.1). Five of these patients said that they had thought that they were getting indigestion, whereas R18 said that initially he thought he was getting out of breath because he was “not fit” and R27 said:

“I thought it was a re-infection, a severe re-infection of this cold that I couldn’t shake off.” (R27)

Seven patients went to see their GP because of the symptoms they had experienced. At this visit they were diagnosed as having angina and were referred to a cardiologist at a local hospital for further investigations, which led to them having a CABG. Two of these patients (R19 and R28) talked about going to see their GP because they were frequently getting what they thought was indigestion, whereas the other five patients (R18, R21, R22, R23 and R26) went to see their GP after having had a single episode of transient but quite severe symptoms. R18 explained that he had been on a walking holiday in the Lake District when he started to get short of breath:

"I was in the Lake District and I got up to about two and a half thousand feet on this particular walk...there was a still a bit to climb and I got really desperately short of breath to the extent that I almost passed out and it was such a, shall I call the air ambulance! Anyway I sort of recovered and I got down under my own steam but obviously it rang a lot of alarm bells."

(R18)

R21 explained that she had experienced chest pain when she was walking with her husband and "had to sit down". This had prompted her that she "ought to go and get it checked out" because she realised that it was not just because she was "getting old". R22 said that he had parked his lorry and was "winding the legs down" on the trailer when he had "got this terrible pain and I was out of breath and that", which had made him realise that he had "got to go to the doctor's, there's something wrong". R23 said that he "suddenly got some awful chest pains" when he "had to scoot for a bus" on holiday" and that "after sitting down and resting for a while it went off" but went to see his GP when he got home "after pressure from the wife". R26 said that:

“It all started when we were on holiday in Turkey. You see we live in a bungalow so I wasn’t used to walking up and down the stairs and we went in one of the top floors in the hotel and I came down one morning to go by the pool and I was puffing and blowing, that’s how it really started.” (R26)

Three patients (R20, R24 and R25) had been to see their GP for another reason when they were diagnosed as having angina and were then referred to a cardiologist at a local hospital for further investigations, which led to them having a CABG. R20 said “I went to the doctor and asked him to investigate whether I’d got prostate cancer because I’d got a pain in the right testicle” and said that when the doctor asked him about any other symptoms he had said “I get short of breath and get a pain there and thought it was indigestion”. R24 said that he had gone for a routine check up with his GP in relation to his high blood pressure when he had been asked about other symptoms and R25 said that his symptoms were picked when he registered with a new GP after he moved back to the UK from Spain.

The remaining three patients (R16, R17 and R27) had had angina for a long time and were only referred to a cardiologist by their GP when their angina became more severe and more frequent. R16 explained that he had “some very bad turns” when he had been on holiday in Spain and had been to see his GP on his return, who had referred him to a cardiologist, whereas R17 and R27 said that they had gone to see their GP because their angina had gradually “got worse”.

Six patients (R18, R20, R21, R23, R24 and R26) talked about it having been a shock to be told how serious their condition was. R20, for example, said that it had been a

“shock and a surprise to be told it was a serious heart condition” and that “it took me a couple of days to get over it”, whilst R21 said:

“Well I don’t think we recovered from the shock for about thirty-six hours. It was a shock, it was a hell of a shock.” (R21)

It seemed that one reason for this was because they did not feel “ill”, as might be expected if they had had influenza, for example, where symptoms were ongoing and persistent rather than episodic and only on exertion. This appeared to make it difficult to reconcile what they had been told about the seriousness of their condition against how they physically experienced their condition. R21, for example said that when she had been in hospital waiting for the operation she had “wandered round because there was nothing basically wrong with me”. R26 said “whilst I wasn’t ill, I mean, I couldn’t walk very far” and R23 said “even, you know, the day of the operation I said to the wife I don’t feel ill”. R18 said that he found the term “disease” to be:

“...a bit of a misnomer in relation to your heart because as I say it’s not like malaria, it’s not like something that makes you feel ill.” (R18)

After talking about their symptoms and the seriousness of their condition being diagnosed, patients tended to give little detail about the sequence of events that occurred in between being referred to the cardiologist at the local hospital and having their CABG at a tertiary care hospital in a nearby city. Five patients recalled having the “treadmill test” done at the local hospital, four patients only referred to having “tests” done, whilst the other four patients only talked about having seen the cardiologist. Ten

patients recalled having an angiogram done at the tertiary care hospital before they were told that they needed a CABG and five patients recalled how long they had had to wait in between first seeing a cardiac surgeon and having their operation. R20 said he had waited “six to eight months”, R22 said four months, R23 said six months, R26 said nine months, whereas R21 said “I had the angiogram and they turned round and said they weren’t going to let me home because I’d got to have this bypass, things were quite bad”. She added that “on the twenty-sixth of October, I was in there from the eighth to the twenty-sixth, I had my operation”.

7.3.2 The impact of having heart surgery

When patients were asked about the impact that their illness and their operation had had on their lives they tended to respond by comparing how much their symptoms had affected them prior to their operation with the improvement in their health as a result of having the operation. This seemed to demonstrate how much their symptoms had affected their lives and that having the operation had considerably lessened the impact of their illness on their lives.

Five patients (R16, R18, R19, R26 and R27) compared how much their symptoms had affected their ability to undertake certain activities prior to their operation and how much easier they could now perform these activities. R18 said “it’s been a bloody awful year” but said that he was “better than I was” and added that he was now able to go fell walking again and had “been to the lakes this year”. R26 said that prior to having his operation he could only “walk a little distance” before he “would have to stop” but said that after the operation he “felt brilliant” and did not become short of breath when walking. R16 said a lot about how his angina had restricted what he had been able to

do but said that the operation was “like the end of a long journey” and although he still got angina, it was almost back to how it had been when it was first diagnosed nearly twenty years previously. He said that he was more able to do things than he had been before his operation, and that his “head is clearer” and his “eyesight is better”. He talked about having increased confidence in his ability to do things without getting symptoms, and as a result had decided that he and his wife would be able to cope with a caravan and a dog again, which they had subsequently purchased. R19 said “I’m not a hundred percent or anything but a lot better than when I went in and had it done like” and pointed out that although he “can’t go running miles or do a marathon you know” he did not become short of breath when walking as he had done previously:

“Well before I had my operation, for me to walk down to the town I would have had to stop every, six or seven times you know.” (R19)

R27 explained that prior to having his operation his angina had become “very, very bad” and subsequently he “tended to avoid situations where it would happen”, which had restricted his life a lot. He said that after he had had the operation “I did not get any angina whatsoever” even in situations that had been particularly likely to cause symptoms:

“Certainly cold winds don’t bother me and that used to be terrible, if I walked from the back garden round to the front of the house on a cold day I’d have to stop for a couple of minutes to let this pain drain away.” (R27)

Seven patients (R17, R20, R21, R22, R24, R25 and R28) talked about no longer getting chest pain as a result of having the operation. For example, R17 said that his pain had now “completely gone” and R24 said “the pain was up here and round the back you know” but added that this “has gone now”. R22 said that not getting pain had given him “a new lease of life” and R28 said that the pain “meant I couldn’t do what I wanted to do” but the operation had improved his “quality of life” because he did not get chest pain anymore.

Five patients (R16, R17, R19, R22 and R26) emphasised how much they thought the operation had improved their health by talking about no longer needing to use their GTN spray or how much less they now used it. As was discussed in section 6.2.1, some heart attack patients also talked about GTN in this way to emphasise perceived improvements in their health. R22, for example, said “I still carry an angina spray, I don’t have to use it very often” and when talking about how much less he used his GTN spray, R16 commented that:

“What they say now is if you spray [GTN] twice and it hasn’t gone then you ring an ambulance, well it would have been permanently parked out here wouldn’t it? [Laughs]” (R16)

In contrast to the other patients, R23 said “it’s an operation that’s certainly not improved my health” and “it’s not given me a new lease of youthful life” even though he had not experienced chest pain since and had been back playing in a brass band “within two months” of the operation. This was because over the “six to nine months” prior to the interview (which was just over two years after his operation) he had started to get short

of breath when doing activities such as climbing stairs, gardening or walking and that “it’s been getting worse in the last two months”. He said that he had not experienced this before his operation and the only symptom he had experienced at that time was chest pain, which had not been frequent because “I didn’t run about a lot and chase about”. He said “I can’t walk more than a couple of hundred yards without you know being breathless” and added that on a recent holiday he had had to be taken to the airport departure gate in a wheelchair. It seemed that this reduced ability had affected his self-esteem because he said “you know this is not me really being pushed past all the other people that was walking to the gate” and added “I did feel a right chump”. He added, “I’ve started using a walking stick and I feel self-conscious about that as well”.

Despite the perceived improvement in their health, seven patients talked about having experienced physical problems as a result of having had the operation that persisted after being discharged from hospital. R27 talked about experiencing “problems with taste” where he got an “awful aftertaste” after eating “that lasted for several months after I got home”, whilst four patients (R16, R20, R21 and R24) talked about experiencing problems with the scar on their chest. For example, R21 said that although she had got a “neat scar” she had initially experienced “an awful lot of skeletal pain” and still found discomfort from clothes that “rub” on her scar such as bras. R20 said “if I bend to turn round like, that hurts me sometimes”, whilst R16 said:

“I still get a bit of pain here in my scar but it’s a lot less than it was so presumably in a couple of years it will go altogether.” (R16)

Three patients (R22, R24 and R26) talked about experiencing problems with the wound on their leg healing where veins had been taken to form the bypass grafts. R24 and R26 only remarked that it had taken a long time for their leg to heal, whereas R22 described the problem he had had with his leg in more detail:

“...one of my things was seeping wasn’t it, in my leg. They put a dressing on it cause it wouldn’t heal up and this one here, I had what they call a big haematoma in this one here, it come up like a bloody egg here!...You know so apart from that, that’s the only thing I had, that little bit that was seeping down there, it took a long time to heal up didn’t it.” (R22)

Only R26 talked about how his illness had affected him financially, since he had had been on sick leave since shortly after diagnosis and had reluctantly had to take early retirement from his job. When asked about the impact his illness had had on his life he said:

“I mean it crucified us financially because I was off work and so then from a reasonable salary to I can’t remember what it was, fifty pound a week and I’ve not worked since. Financially, yes it crucified us, we was even thinking of selling our car, truly it was that bad, it’s not so bad now.” (R26)

He added “after the operation I honestly thought that after a couple of months I could go back to work” but pointed out that his “doctor wouldn’t let me go back” and that “it took about two years before I accepted that I wasn’t going to go back to work again” by which time he was sixty-five and would have retired anyway. R19 and R28 had also not

been able to go back to work after their operation, whereas the other patients had retired some years before their operation, although R22 said that despite having retired he used to “go on odd trips” as a lorry driver and it had been on one of these “trips” when he had first experienced symptoms. R19 said “they won’t let me go back to work” and that he had “given up” asking his doctor whether he could go back because he had been “feeling the strain” at work before he had the operation and “I’ve only got two years to go really and I’ll be retired”. R28 explained that since after his operation he had been getting a “sick note” from his doctor every six months. Neither he nor R19 said anything that suggested that they had experienced financial difficulties as a result of not working.

7.3.3 Use of health services and patient groups

All of the patients expressed their gratitude towards the health professionals who had been involved in their operation and their care afterwards, especially the cardiac surgeons and the nursing staff. For example, R21 said about the hospital staff “to be quite honest they were fantastic, everybody was fantastic in there, I can’t speak too highly” and R26 said “I’ve only got good things to say about them all, truly”. Similarly, all of the patients indicated that they had found the CR programme beneficial and particularly the exercises, although when asked about their experiences of CR, they tended to say much less about it than the heart attack patients had done. For example, R24 said about CR “that was good, we did a few exercises and they did your blood pressure and checked you as you went along and yes that was fine”, R21 said CR “was great”, although she added “but there was only one other person that had had a bypass, they nearly all had heart attacks”, whilst R26 said “I used to go every week for exercise...that went on for about six weeks, that was very good”.

With the exception of R23 who saw his GP on a regular basis again, all of the patients reported that they saw their GP less often than they had done prior to their operation and now only for approximately six-monthly checkups. It seemed that, as with the heart attack patients (section 6.2.2), this had confirmed their perceptions of their health having improved. In addition, patients had had little, if any, contact with health services or patient groups in relation to their heart and minimal contact with health professionals in general. This was also found with heart attack patients (section 6.2.2) and similarly seemed to have been because patients chose not to. Seven patients (R16, R17, R24, R27, R21, R22 and R28) gave a reason why they had chosen not to make contact with a patient group such as R24, for example, who said “I didn’t feel any need after I’d done that rehabilitation thing for six weeks” and R28 who said “I could have done but you know, not interested”. R27 said “I must admit I wasn’t interested, to me that’s dwelling on what’s happened and it’s gone” and added “there’s too much else to get on with”. R27 said “I didn’t seek any out to be quite honest” and added “I’m mainly busy doing other things anyway”, whilst R22 said:

“I think people just get on with their own lives and do their own sort of thing, that’s what we’ve done haven’t we. I mean it’s not that we’re too bloody miserable to get to one, we’ve just got our own lives.” (R22)

7.4 Perspectives on the risk of serious CHD-related events

It seemed that all of the patients had made the decision to have the operation after having assessed the risks of serious CHD-related events happening (e.g. heart attack or death) if they did *not* have the operation, although eight patients also talked about

having assessed the risks of *having* the operation (as is discussed in section 7.4.1). Having had the operation, it seemed that patients no longer saw themselves as being at imminent risk of serious CHD-related events because they perceived that in being preventative the operation had resolved the problem, or significantly reduced it (as is discussed in section 7.4.2). As such, when patients were asked whether they thought they might have further heart-related problems all of them talked about their longer-term risk, which they tended to view principally as being a matter of bad luck or chance. This seemed to be related to what they thought had caused their CHD (section 7.4.3), particularly since only two patients cited aspects of their lifestyle as likely causes. None of the patients appeared to be fearful about the risk of having a serious CHD-related event in comparison to the heart attack patients (see sections 4.5.1 and 6.3.2).

7.4.1 Pre-operative risk assessment of serious CHD-related events

It seemed that what patients had been told about the risk of having a serious CHD-related event if they did not have the operation had been an important factor for all of them in making their decision to have the operation, as well as the prospect of it resulting in them no longer experiencing symptoms. All of the patients talked about this when talking about the seriousness of their condition being diagnosed, without needing to be specifically asked about risk, and was expressed in three ways: six patients (R20, R21, R22, R24, R25 and R28) talked about their risk of dying, reduced “life expectancy” or not “being here” for much longer if they did not have the operation; three patients (R18, R23 and R27) talked about their risk of having a heart attack; whilst the other four patients were less specific about the nature of the serious CHD-related event that might happen if they did not have the operation.

R20 and R28 talked about not having the “life expectancy” if they did not have the operation, whilst R24 talked about only having “a year to live if I don’t have it done”. R21 said “if I didn’t have it done I wouldn’t be here the following September” and that she had been told that if she had not had “anything done, within twelve months you’ll have a heart attack, at the worst you could be dead”. R22 put it in retrospective terms by saying he “wouldn’t be here now” if he had not had the operation and that afterwards he had thought “I could have had a bloody heart attack”. R25 said that when the doctor had told him how serious his condition was he had said “I’m not ready yet to go, I’d better have the operation” and that:

“It’s one of those things, you know, you either wait for something to happen or you get it done. We decided to get it done; I wouldn’t be here now otherwise.” (R25)

R18 said that he had been aware that he “must be a pretty high risk of heart attack” because “one of the main arteries was ninety-nine percent blocked” and there had been “no real alternative” but to have the operation. R27 said “I’m fortunate that it was spotted when it was and I’ve never had a heart attack”, whereas R23 said “I was feeling why should I bother because obviously I wasn’t running for any more buses” but had then decided:

“But I suppose once they saw that the arteries were narrowed I thought best to have it done in case I suffered a heart attack” (R23)

R19 and R26 both said “who knows what could have happened” if they had not had the operation, whilst R16 talked about being aware that he was at increased risk, which he had particularly thought about when he experienced prolonged episodes of angina and R17 said that being told that his condition was serious “had set alarm bells ringing”.

Eight patients (R18, R19, R20, R21, R22, R24, R25 and R26) also talked about being apprehensive about having the operation, at least in part, because of the risks of not surviving the operation, post-operative complications, or experiencing severe pain. For example, R18 talked about being concerned about the operation when he was told that in his case there was a “ten percent of not surviving” and R25 said “I was very low because you hear all sorts of tales about major operations, they can go wrong”. However, six of these patients talked about being “reassured”, “put at ease” or feeling more “confident” by talking to either doctors or nurses or other people who had successfully had the operation. For example, R19 said “well I was concerned mind you before I went in and had it done like, wondering this and the other and when I went in they put you so at ease”. R20 and R24 said:

“Anyone you spoke to who’s had heart surgery, either valves or bypasses or even worse than that said that they felt better afterwards, it all gave me a great deal of confidence then and it would be great in the future.” (R20)

“I was worried but I had spoken to somebody who’d had the same thing done and they said that they went in and they were out of bed in a couple of days and it was like that...they did tell me that you didn’t feel much and it was alright so that put me at my ease a bit.” (R24)

7.4.2 Post-operative risk assessment of further CHD-related events

Having had the operation, it seemed that patients no longer saw themselves as being at imminent risk of serious CHD-related events because they perceived that in being preventative the operation had resolved the problem, or significantly reduced it. This was shown in the way that patients talked about how they thought their heart was now functioning (which was similar to the way that heart attack patients talked about this, as discussed in section 6.3.3) and what the operation had achieved. In addition, when patients were asked about whether they thought they might have further heart-related problems, all of them talked about it in terms of longer-term risk and did not seem to be fearful about it as the heart attack patients had tended to be (see sections 4.5.1 and 6.3.2). To a certain extent, this may have been due to there having been a longer duration of time between the surgery and the interview than between the heart attack and second interview with the heart attack patients (i.e. they may have previously been fearful but not by the time of the interview). However, there was no time difference with three patients (table 5, section 7.2.1) and the way that patients talked in terms of being at much lower risk than they had been prior to their CABG surgery suggested that it was unlikely that they had been as fearful at any point after their CABG surgery as the heart attack patients had tended to be after their heart attack.

Two patients (R17 and R22) talked about the operation having resolved or “cured” their problem, although they did not discount the possibility of having further heart-related problems in the future. Eight patients (R16, R19, R23, R24, R25, R26, R27 and R28) talked about the operation having resolved the most serious heart-related problem but were aware that less serious problems remained. These patients talked about their longer-term risk of further-heart related problems principally in terms of it being a matter

of bad luck or chance, although two of them (R27 and R28) also talked about medicines reducing their risk. The remaining three patients (R18, R20, and R21) talked about the future in terms of the operation having prolonged their life and implied, rather than explicitly saying, that they thought they might eventually die from their heart condition.

Of the two patients who talked about the operation having resolved or “cured” the problem, R17 said:

“As far as I’m concerned it’s like a car engine, the engine is the heart and the fuel pipes are the ones that were blocked. So as far as I’m concerned they cleaned out the pipes.” (R17)

He pointed out that “to me it was relatively minor” and did not think that there had been any damage to his heart because “I’m in the fortunate position that I’ve never actually had a heart attack” and added that “the one they keep coming back with is, oh yes you’ve got the heart of a forty to fifty year old, so it’s pumping quite strongly”. When asked whether he thought he might have further heart-related problems he said “as far as my heart is concerned I’ve forgotten it” and added that he did not worry about the future because “I had a completely relaxed attitude to it all”. In addition, he pointed out that “it took sixty years to block up so I’ve got another sixty years [laughs]”. R22 said “they caught it and they cured it and that was it” and when asked when he thought he might have further heart-related problems he said:

“You know, I mean you couldn’t wish for anything better really you know, I mean as I say they cured what I’d got wrong, well I think they have

anyhow. And as I say I still carry my angina spray, I've got it here just in case 'cos he said it could come back, you know so. But if you can help yourself like that then I can't see any problems myself. I mean I've heard of people, there's an old fellow who comes here who had a double bypass twelve years ago, he's seventy odd isn't he. He mows his lawn, he digs, he bloody drills, he does everything and he's seventy odd! Twelve year ago he had his bypass!" (R22)

Of the eight patients who talked about the operation having resolved the most serious heart-related problem but were aware that less serious problems remained, R25 said that he had a single bypass done but had other two arteries that were "furred up" that had not warranted being bypassed at that time. He said that he was "conscious" of this because "obviously they're getting worse" but pointed out that "even at my age I don't think about dying" and that:

"When you're seventy-seven, I mean that's the thing at the back of my mind all the time, but these things are going to happen you know to people younger than me and I think you've not done too badly. So as I say I'm not the type to worry about and dwell on these things, if they happen they happen." (R25)

R26 explained that he had been told that he needed a triple bypass but the surgeon had only done a single bypass because during the operation it had been discovered that "two of them weren't that bad". He said that he had to have an annual exercise stress test (the "treadmill" test) and that if he did experience further symptoms "they'll

refer me back and if necessary then I'll have to have the other surgery". As far as his GP was concerned "that was one of the reasons why he'd never let me back to work", even though from his own point of view "I never felt ill and I never had a heart attack or anything" and "I didn't want to be retired". He added that he did not worry about "anything" going "wrong" (especially that he might die) but said "I suppose if I was ill and in pain I'd worry". He emphasised this point by comparing his lack of worry with somebody who he considered to be at higher risk of dying than himself who apparently did not worry either:

"Normally about most things I worry about myself up to a point but no I don't think of myself, I really don't because I feel pretty good. If you feel ill, I mean I worked with a chap who'd had three heart attacks, and these days I think two and that's your lot, and this chap had had three and he used to drink whisky and beer like a fish, smoked forty a day but that man's in [at work] twenty-four hours a day! I mean officially he shouldn't have been alive! And he wasn't afraid, he said well if it's my time I won't wake up and in fact it's a good way to look at life without worrying about what's going on. I think if I felt ill or in pain we wouldn't be having this conversation but I don't." (R26)

R27 said "generally I think I'm fortunate that it was spotted when it was and I've never had a heart attack you see, and my heart apparently wasn't damaged even though I'd had angina", since "if you're hit with a heart attack and bang, down you go, that's a different kettle of fish I think". He was aware that he still had an artery that was "only partially blocked" but said that if he was "unlucky enough" to need further surgery that:

“Certainly if you need to have it done [further surgery], I’ll go ahead and do it [laughs] but hopefully that won’t be necessary, I mean it doesn’t worry me, I think we’ve got the medication right...I’m not worried that oh I’m going to have a problem with this artery.” (R27)

His reasoning for why he thought “we’ve got the medication right” was related to reducing his cholesterol level and is discussed further in section 7.6. R28 explained that he had “big arteries”, as a result of being “super-duper fit” in the Navy for “twenty-four and a half years” but had needed a “double bypass” because when he had had an angiogram he had been able to see that the “walls outside” his arteries had “collapsed” in places and “had gone inwards”. He pointed out that “I still have a share of heart disease, even though I’ve had the operation I’ve still got a disease” and that his GP put on his six-monthly “sick note” that he had “ischaemic heart disease”. When asked whether he thought he might have further heart-related problems he said:

“I hope not, you know I mean these people with this, I mean there’s one, these people that have had it before come round and see you, I mean one woman she said she’d had it thirty years ago. One bloke come in and he were fifteen year ago...but it doesn’t mean to say that in the rear arteries or whichever ones they didn’t do, who’s to say that they’re not going to end up collapsing like these did? So it’s still there isn’t it, but at least I know they’re still there at the hospital so I can get it done if it needs doing. You know, I mean because you know the symptoms. I mean I’m not always on the lookout for them but I know what they are if I ever get it again, you see that’s the thing.” (R28)

He added that he was not worried about the possibility of having further CHD-related events because “you can feel it coming on, you know you feel it coming on” and later said “I mean me with my heart, I think I can go on forever, it’s just the rest of me that’s falling apart”. He talked about his risk of further heart-related problems being reduced by taking medicines (section 7.6). R16 said that “they were going to do a triple and for some reason, which they never explained to me they didn’t do the triple they did a twin, something to do with the veins”. He added that they had taken veins from his leg “but apparently they were no good” and so he still got angina, although substantially less than before (as was discussed in section 7.3.2). When asked (in the second interview) whether he thought he might have a serious CHD-related event in the future he said:

“But I don’t worry about it and think oh dear am I going to have a heart attack. When I’m going to have my heart attack I’ll have it you know. I don’t think there’s anything I can do to stop it. I take exercise and I’ve lost some weight, we don’t drink a lot and we don’t smoke, we don’t eat a lot of fat things do we, junk food.” (R16)

R19 said “they showed me a diagram of my heart like” and that the surgeon had said to him “you imagine a blocked drain...well that’s your heart presently blocked”. He explained that “now what they’ve done now they took the artery from my leg and put it in the, you know, I feel a lot better now”. When he was asked whether he thought he might have further heart-related problems he said “I hope to carry on for a few more years like you know” and that “as long as I take it easy, you know I’ll be alright you know”. He also said “people ask me like you know, what’s the lifespan on it you know” and added:

“Well I’m hoping it’s a lifetime but I don’t know what the answer to that is to be honest with you. I should have asked them, I’ve heard of people having to go back in and have it done again so I don’t know.” (R19)

R23 explained that he had not had any symptoms after he had had the operation but had recently started getting short of breath (as discussed in section 7.3.2), although his GP “didn’t seem to find anything unduly wrong you know” when he went to see him. When asked whether he thought he might have further heart-related problems he said:

“I don’t think my heart is going to get any better because I’m not an expert so I don’t think it’s going to improve a terrific amount as long as it stays as it is at the moment I suppose I shall be quite thankful.” (R23)

He also said “my father was ninety-three when he passed away, so I’ve got a little while to go yet” and when asked whether getting breathless worried him he said:

“No, I don’t think so, I’m not in any chest pain or anything like that. If I was I should certainly be annoyed and running off to see the doctors but I’m not, tomorrow night I’m playing in a concert, which with that I’m hoping with the heart I’ll have no problems.” (R23)

R24 said, when asked about whether he thought he might have more heart problems “well I do because my Dad died at fifty four and I’ve got two sisters, one’s recently had a heart attack and the other one suffers with her heart”. He then talked about the lifestyle

changes he had made since his Dad died (this is discussed further in section 7.5) and said that he hoped he would be “ok” now that he had had the operation.

Of the three patients who talked about the future in terms of the operation having prolonged their life, R18 said:

“They only gave me one bypass, the other two arteries were too thin to be able to make a connection, actually by doing the main one the others would naturally improve and so I’ve gone from there” (R18)

He pointed out that he had “survived without a heart attack and come through” and when asked whether he thought he might have further heart-related problems, he talked about not being concerned but said, partly jokingly, about only having “nine years left”:

“I’m aware of this thing, as they say ten to twelve, right I’ve had a year so I think right I’ve nine years left...I mean I joke because obviously you tend to think it’s that way. I’m not going to worry about that until it starts to get within a year or two!” (R18)

R20 said that when he had an angiogram the “man in charge said you’ve got a serious heart condition” and that he was “right clogged up”. He pointed out that “I’m now seventy-six and I’ve got four children” and when asked whether he thought he might have further heart-related problems he said:

“Well they said when I had the surgery that it would probably give me at least five to ten years and that was a very big bonus as far as I was concerned with a young family...I have no concerns about the future apart from the fact I won’t see my children grow up. If that’s at all possible, just to their teens to give my partner now, help.” (R20)

R21 said “I feel now I’ve gone through it, hopefully I’m going to be around for a lot more years” and when asked whether she was concerned that she might have further heart problems in the future she said:

“No, no I’m not, I do think about the future, you now things crop up like I want to see my granddaughters and I want to see them grow up and get to college and do all the things they want to do but I think that’s natural, I think so.” (R21)

7.4.3 Explanations for the cause of the CHD

Nine patients seemed uncertain about what they thought had caused them to have heart problems. Despite this, all of the patients talked about lifestyle factors that they thought could cause CHD but only two patients appeared to think that aspects of their lifestyle had been likely causes of their CHD. In contrast, the heart attack patients tended to cite aspects of their lifestyle as likely causes of their heart attack, although they too tended to be uncertain (see sections 4.4 and 6.3.1). Of the aspects of lifestyle that were mentioned, only R26 mentioned stress as a possible cause of CHD, compared to the heart attack patients who commonly talked about stress (job-related or otherwise) as a possible cause of their heart attack.

When patients were asked what they thought had caused them to have heart problems, R16 and R22 cited aspects of their lifestyle as likely causes, four patients (R17, R24, R27 and R28) cited heredity as a likely cause, R18 and R25 talked about it being a matter of chance, R19, R20 and R21 suggested other possible causes, whilst R23 and R26 did not actually suggest a likely cause. Of the nine patients who seemed uncertain about what they thought were the likely causes of their CHD, seven of these patients cited possible causes but all nine of them pointed out that they did not think aspects of their lifestyle had been likely causes. In contrast, the other four patients (R16, R22, R24 and R28) seemed to be more certain about what they thought were the causes of their CHD, two of whom (R16 and R22) cited aspects of their lifestyle as likely causes.

Of the nine patients who seemed uncertain, R17 and R27 cited heredity as the most likely cause. R27 said that he thought he had a “familiar history” because his grandfather “died of heart disease” but said about his father “I don’t know whether he had angina or not”. He seemed uncertain about this explanation because he said that the cause was “blinking unknown” but said “so it’s not lifestyle that’s brought it on” and pointed out that he “stopped smoking thirty-odd years ago”. R17 said “I tend to think now it’s hereditary because my father had it”, although this suggested he that he may have remained rather uncertain about it and “tended” to think this because “there’s nothing else I can think of”. In contrast, he seemed rather more certain that “bad eating” had not caused it:

“They said it was due to bad eating, but it’s not possible because many, many years ago I had jaundice very badly when I was relatively young,

which meant I always had to be careful with what I ate. Low-fat, ever since they came out, low-fat stuff.” (R17)

R18 and R25 talked about it being “one of those things” or “it just happens” (i.e. bad luck or chance). R18 said that he did not know what the cause of his heart problems had been because “I’ve done all the right things”:

“That I don’t know, I mean it’s just basically the arteries get furred up and it just happens. My cholesterol has never been particularly high, I’ve had it checked once or twice in the past and it’s never been sky-high, so you tell me I don’t know...I’ve been reasonably fit all my life, I’ve walked a lot, both pleasure and with work a lot, and you can see I’m not overweight, never have been. I’m not a particularly heavy drinker, I’ve not got diabetes, never smoked, because these are all things they say are at risk of heart disease.” (R18)

R25 said that he “assumed” his coronary arteries “getting furred up” was “quite a common thing in old age”, which suggested that he was uncertain about it. He pointed out that he had not smoked for “many, many years” and that his “wife made sure I had a healthy diet”:

“So I don’t think there was anything in my lifestyle that would have caused my arteries to flare up like that, I think it was just one of those things.” (R25)

R19, R20 and R21 suggested possible causes but discounted aspects of their lifestyle as likely causes. R21 said “I don’t understand why I got this” and pointed out that she had “always really eaten healthily”, that she had not smoked for “over thirty-odd years” and that her “cholesterol was ok”. The only possible cause she could think of was her high blood pressure, whilst R19 did not think that diet or lack of exercise had been a cause of his angina, had never smoked and said:

“I worked fifteen years in the steel works when I was younger so I don’t know, that could’ve helped it like, I don’t know, I never lifted anything heavy like machinery you know, I never worked underground or anything. So what was the run up to it I don’t know, I don’t know what caused it. In [his town] everything’s flat, it’s not hilly or anything like that. So I don’t know like what caused it I couldn’t say. Like I say it isn’t smoke so they can’t say it’s your smoking that caused it.” (R19)

R20 said that he had stopped smoking “many years ago”, had always been “reasonably active” and that he did not drink alcohol. He said that he did not know what had caused his heart problems but added:

“I presume it’s old age and poverty, you know I suppose you know an engine in a car that’s seventy-odd years old is getting to be past its best, it needs a re-bore or reconditioning. So you know the human body must be about the same probably.” (R20)

R23 and R26 said that they did not know what the cause had been and did not cite any possible causes, although they did discount aspects of their lifestyle as likely causes. For example, R26 said that he “used to smoke” but had stopped a long time before he first experienced any symptoms, whilst R23 said:

“I don’t know because I’ve not smoked since I left the Navy when I was twenty-two and I’ve not smoked since then so I don’t know why it happened.” (R23)

In contrast, four patients (R16, R22, R24 and R28) seemed more certain about the cause of their heart problems. R28 said that he knew “it’s hereditary” because that was what he had been told by his doctor and that “it wasn’t cholesterol” because he had seen on his angiogram that his artery walls had “collapsed”, rather than having “furred up”. He emphasised that he did not think his lifestyle had been the cause by saying:

“I was so fit, I mean why all of a sudden should I end up with narrowed arteries?” (R28)

R24 said that his dad had died of a heart attack when he was fifty-four and that his sisters also had heart problems. As such, he seemed more certain that heredity was the cause, especially since the doctor had told him that “this thing was genetic sort of thing really”. He did not think that his lifestyle had been a cause because:

“Since my Dad died at fifty-four we did change our eating habits and since then we do try to eat reasonably well...not overweight and all the rest of it.”

(R24)

R16 said that he used to be a “very heavy smoker” before he had stopped some “twenty-five years, possibly thirty years ago” (i.e. ten to fifteen years before he was first diagnosed with angina) and said that “all my complaints that I’ve had, I’ve had cancer of the throat and things and everything basically originates from heavy smoking”. However, he did not seem to think that other aspects of his lifestyle were likely causes. R22 also cited lifestyle as being the most likely cause of his CHD when he said:

“Well I think I put it down to the lifestyle really. You know I mean when we was younger we used to go out on the beer, we used to drink like fish, smoke like troopers.” (R22)

7.5 Perspectives on lifestyle modification

Most patients did not seem to have made lifestyle changes or maintained lifestyle changes that were made after their operation or around the time of the CR programme. This seemed to reflect their view of lifestyle not being the cause of their CHD (section 7.4.3) or that they did not need to change their lifestyle to meet the recommendations that were told about at CR (section 1.2), or both. Those patients who did seem to have changed their lifestyle and maintained those changes tended to have benefited from the change or cited lifestyle causes of their CHD, or both. As such, it seemed that all of the patients took an approach towards lifestyle risk reduction that followed from their

perspectives on their risk of experiencing further CHD-related events, irrespective of whether changes were made or maintained.

Six patients (R17, R18, R24, R25, R27 and R28) did not seem to have made any changes to their lifestyle around the time of the CR programme and explained that this was because they thought they were already doing what they needed to do. R24 explained that he had changed his “eating habits” to eat more fruit and “keep off the crisps and fatty foods and all that” some years previously when his father died of a heart attack, since “we used to eat quite a lot of fatty foods when we were younger”. He said that he continued to play bowls regularly and still did a lot of gardening, since he had “always been quite active, even now I’ve retired I don’t like sitting around”. As far as lifestyle change was concerned he pointed out that:

“I didn’t change because of all of this I just carried on the same as I normally would and the fact that he said my other arteries were open anyway I’d assumed that I was perhaps doing something right.” (R24)

R18 said “we’ve always tried to be a bit sensible, I mean we’ve sort of been aware that you know, we don’t want too much fat in things and things like that” and had “cut down on things like butter and fatty things” when he had “a slightly high cholesterol quite a few years back”. He said “I’ve been reasonably fit all my life” and that he went fell walking on a regular basis, which he had resumed after “building up my exercise” on the CR programme. Subsequently, he did not think that he had needed to change his lifestyle any further. R17 said that he had jaundice “many, many years ago, which meant I always had to be careful with what I ate” and that he had kept to a low-fat diet

ever since. He explained that both before and after his operation “we still get the exercise” and that “even now if I don’t walk down to the shops I’m back on the [walking] machine”. When asked if he had changed his lifestyle after his operation or attending the CR programme he said:

“It wouldn’t have had, let’s say that modifying lifestyle would have brought me to what I do already.” (R17)

R27 said “I don’t think there’s anything he [GP] can tell me about diet and lifestyle because I’ve been looking at that for the last twenty years” since his angina was first diagnosed. He explained that at that time he and his wife had “looked into the things which were bad” with their diet and “went through the larder and chucked anything out and we started again”. He said that he had found the exercises at CR difficult because he had had his left hip replaced and had “severe arthritis” and a “trapped nerve” in his right hip. This had continued to get worse and limited the exercise he was able to do. R28 also said that he had difficulty doing exercises because he had “post-traumatic arthritis of both ankles, some more on my back where I broke it, both shoulders and my fingers” as a result of the numerous injuries that he had sustained during his time in the Navy. He explained that as far as his diet was concerned “I don’t have fat, any fat on anything, I cut it off” and that “I’ve always preferred it that way anyway even before this”, although he said that he had been more careful about his diet since he had been diagnosed with diabetes “type two, which is diet”. He also said “I stopped drinking two and a half year ago, I used to be awful”, especially when he had been in the Navy because “they break out the rum don’t they” and pointed out that he generally intended to continue “not doing what I’m not allowed”. R25 had not previously made any changes

to his lifestyle but said that he had always got “plenty of exercise” and his “general diet was always pretty good” because he took care to eat “good food, the right sort of food”. When asked whether he had made any changes to his lifestyle after his operation or attending the CR programme he said:

“Mmm, not really because we’ve always eaten fairly healthy and very keen on keeping in trim you know.” (R25)

Four patients (R16, R19, R23 and R26) did seem to have made lifestyle changes after having their operation or attending the CR programme but did not seem to have maintained one or all of the changes. R16 said that after finishing the CR programme:

“I used to run around here every morning didn’t I, get myself all warmed up and exercise. I don’t do it anymore of course [laughs] but I still go on the [exercise] bike and have a couple of minutes on the bike.” (R16)

The reason he gave for why he had not maintained the exercise he had initially done was because “I get pain in my legs” when walking or running but did not experience this when using his wife’s exercise bike for a “couple of minutes”. He explained that he had not changed his diet because “we don’t eat a lot of fat things do we, junk food” and “we don’t drink a lot”. R23 said about continuing to do exercises “I find I can’t do them now because I get breathless” but said that he used to go out walking “two or three miles eventually” after he had attended the CR programme since “at my age you don’t go to the gym, anything like that”. When asked about his diet he said that he had been told to

“keep off fatty things but that’s easier said than done isn’t it” and added “we’ve just had fish and chips for lunch [laughs]” before saying:

“Well we always have a tremendous amount of vegetables every day and there’s always fruit in the house that we can eat. I don’t think I go seriously against their recommendations, in fact I can’t remember what the recommendations were now! But obviously it was to be on a low-fat diet, which is difficult to achieve to be absolutely honest because whatever you buy from the supermarket and Marks and Spencer’s and things it’s got fat content hasn’t it. I mean we always have semi-skimmed milk and margarine as opposed to butter, there’s not an awful lot more you can do. I certainly eat a lot of fruit and two or three vegetables on your plate every time you have a roast or something like that. Occasionally we eat fish and chips, which we did today because it’s Friday.” (R23)

R26 said “after surgery you’re supposed to do long walking and I did didn’t I and again it was pretty enjoyable to get out but unfortunately that’s gone by the wayside”. When asked why he said “I couldn’t be bothered, which is a terrible thing to say yes but that’s more to the truth” and that “it’s more like pure laziness on my part”. He had not thought lack of exercise had been a cause of his CHD and had been “quite fit” when he had been at work but said that since he had retired “I am putting on a bit of weight on now and starting tomorrow I’m going to go for a walk”. He said that he had not changed his diet because “I know myself what’s wrong for me, again being a diabetic” even though “most diabetics cheat, we don’t cheat that badly but we still cheat”. R19, who had not thought diet or lack of exercise had been a cause of his CHD, said about his diet “I try

to eat normal or as normal as you can like” and “I have things in moderation” but did not seem to be as diligent about maintaining changes to his diet because he also said:

“I’m not as keen as I was in the beginning. You know when I’d had my operation because you’d do anything the book tells you because you don’t want to go through it again like.” (R19)

On the other hand it seemed that he had maintained the amount of exercise he had initially done after attending CR. He said “I get plenty of exercise like you know” and explained that in addition to walking his dogs for at least an hour each day he went to the gym “about three or four times a week” to use the “bike and treadmill and different things” in order to “keep myself trimmed up a bit”.

Only three patients (R20, R21 and R22) seemed to have made lifestyle changes after their operation or around the time of CR and had maintained all of these changes. R21 talked about enjoying doing a lot of walking since attending CR and said that she had also bought an exercise bike so that she could “use my bike to keep ticking over” on days when she did not go for a walk but talked about not needing to change her diet. R20 said that he had “cut down on certain things because of my cholesterol” and that he had been “trying my hardest to get my weight down” because he seemed to have been dismayed to find out that he was “two stone odd” heavier than he had been when he had been in the fire service. However, he said that he had not got a “physical regime put together” since “with having the four children I’m reasonably physical”. R22, as discussed in section 7.5.1, cited aspects of his lifestyle as a likely cause of his CHD. He had “packed up” smoking (while he was waiting for his operation rather than afterwards)

and now did more exercise by “walking as much as I can” but apart from reducing his alcohol intake talked about not needing to change his diet because he was “borderline diabetic” and was already “a little bit careful with some things you know”. He said that he thought he was doing “everything they told me”:

“They told me to pack up smoking, I packed up bloody smoking, told me to go out walking, I go out walking. I do everything they told me.” (R22)

7.6 Perspectives on taking medicines

7.6.1 Taking the medicines

All of the patients indicated that they were taking their medicines and demonstrated this in one or more of the same four ways as the heart attack patients (see sections 5.3.1 and 6.5.1): by specifically pointing out that they were prepared to take them; by talking about having a strategy to remember to take them; by showing that where doses had not been taken as usual, this had not been intentional; and by tolerating or seeking medical advice about side effects, rather than simply deciding not to continue taking the medicines thought to be responsible (this last point is discussed in section 7.6.2). As examples of patients specifically saying that they were prepared to take their medicines, R20 said “I just take them, it’s part of my daily life”, R28 said “I just throw them down my neck”, and both R19 and R22 said “I don’t mind taking them”. R21, in particular, explained her view about this in some detail:

“Well I think I’ve got to take them haven’t I otherwise, both of the main medicines I take are to help my blood pressure get down, now I know for a

fact that if your blood pressure goes on being sky-high I'm in line for a heart attack. I've been told that blood pressure can give you, really high blood pressure can give you a heart attack. Well I don't want that, I don't want that and I don't want a stroke thank you very much! So if I've got to take these tablets till the end of time then I'm quite happy to do it! I've got high blood pressure but it's controlled high blood pressure. If I didn't take them, well I'm not prepared or willing to take that risk...You know I just take them because I don't want to be ill again, it's not 'ill' is it, I don't want this to happen again. As far as I'm concerned, as I said I'm seventy-two years of age, I want to be eighty-two in ten years time and I don't want to be in a wheelchair! Good God no, thank you very much!" (R21)

Ten patients talked about having a strategy to remember to take their medicines, which involved having a routine (R21, R23 and R26 did not talk about this). As examples of this, R20 described his routine for taking his medicines as being "a part of getting up" in the morning and R17 said "you set up a routine, you stick to it". R25 explained that he had got a "little tablet organiser" and "every Sunday morning" he sorted his tablets out for the week ahead. He said about his routine:

"You know, you asked earlier you know how you feel after having the operation, how it's affected your life. I suppose subconsciously there are things that you know you've got to do and you do them; you programme yourself to do them and taking tablets is one of them. You know, you realise that they're for the good of your health, if you didn't take them you'd probably suffer. So you get into this routine, as I say every Sunday I sort

them out and every morning when I have porridge for my breakfast, while I'm getting that I sort my tablets out for the day and you know it's like everything else in life, there's a lot of routine in life. (R25)

Six patients (R16, R18, R20, R23, R25 and R27) talked about occasions where doses had not been taken as usual and pointed out that this had not been intentional. For example, R18 described his daily routine for taking his medicines and added "having said that, I do occasionally forget", whilst R23 said about the occasions when he did forget to take his medicines that "I don't deliberately not take them". R27 said that he occasionally forgot to take his aspirin until later in the day because "I have to dissolve it into water and I may go off and do something and forget that I've got it dissolving" but added "I would never not take it". Similarly, R25 said that he "very, very seldom" forgot to take his medicines at all but occasionally forgot to take them until later in the day:

"You're supposed to take it the same time every day, sometimes I put them out in the kitchen ready to take them then I forget and my wife will bring them in and say you haven't taken your medicines...I mean I do take them, although it may be two or three hours later than they ought to be."
(R25)

7.6.2 Views about taking medicines and approach to medicines information

All of the patients reported that they had been given written information (for example, patient information leaflets supplied with medicines) and verbal information about their medicines by a least one health professional, as was similarly found with the heart attack patients (section 5.3.2). It seemed that the information that patients were given

tended not to be individualised and had only partly helped resolve their medicines-related concerns. Nine patients expressed a sense of disquiet about taking medicines, mainly by raising their concern about two particular issues: firstly, experiencing side effects or concern about the potential for medicines to cause side effects; and secondly, concern about the potential for medicines to cause long-term problems. In contrast, four patients (R19, R20, R25 and R26) did not appear to express any disquiet about taking medicines. As discussed in section 5.3.2, the heart attack patients raised concerns about side effects, whereas concern about the potential for medicines to cause long-term problems was not raised.

Seven patients raised concerns about side effects of medicines, of whom six patients had experienced side effects, whilst R22 was concerned about the potential of medicines to cause side effects. R17 appeared to express the strongest sense of disquiet and said about taking medicines that he was “not the sort of person that will be convinced by the wave of a hand, you’ll have to convince me it’s beneficial”, since:

“I’ve never been in favour of taking medicines or anything too much because aspirin, anything like that, even beforehand I wouldn’t take. I always reckoned that if you have a headache, you want a breath of fresh air to clear the head.” (R17)

He seemed to have been “convinced” that the medicines that he had been prescribed were “beneficial”, with the possible exception of his atenolol. He said that he was “not really happy” about the side effects of atenolol, which he had become particularly aware of when he had omitted his medicines prior to having the “treadmill test”, had felt

“physically better” and thought that the atenolol was “the one that’s causing the problem”. He said that he intended to discuss with his GP whether he still needed to take it because when he had read the information he had been given about it he could “understand it for a period immediately after the operation because it might help to ease, take a load off the heart but we’re now talking eighteen months plus”. R16 said about his medicines “I was taking them over a long period of time so I became aware of what they were for” and explained that “each time something else was added I sort of read the pamphlet to find out why I’d got it”. He also said that he had got an old copy of the British National Formulary, which he used to look up “all the side effects”. He talked at length about various side effects he had experienced over the years, particularly the “really bad cough” caused by ramipril and said “you wouldn’t have believed that anyone would recommend a tablet that would let you get in that state”. He pointed out that on each occasion he had discussed the problem with his GP, rather than having just stopped taking the medicine he thought to be responsible but talked about “trusting” the consultants more than his GP to prescribe medicines that would not cause side effects:

“I go to them [Consultants] for help and therefore I believe them but I wouldn’t trust my GP, give him that much faith because generally speaking he just pulls out a book and looks at it and gives me one of half a dozen that are in the book and then if it doesn’t work then you go back and say it doesn’t work and he will take one of the others and he’ll pick one until he finds the one that doesn’t give any side-effects.” (R16)

R18 expressed disquiet about taking medicines when he said that he had “never been a pill person” and used to view taking medicines as being “an old people’s thing”. It

seemed one reason for this was that he was concerned about the potential for medicines to cause side effects:

"I always make a point when I get another tablet for whatever reason I always look at the leaflet that comes with them, mind you that's not a particularly good idea because you can guarantee it's got some side effects. Diarrhoea, constipation, they always have those with them and you think bloody hell I don't want to be taking these." (R18)

He gave an example of why he was concerned about side effects by talking about having become "very light headed" and "was falling over you know" after he had been started "on a tablet, which helps to relax the prostate" and added that "when I looked at the thing it also acted a little bit like a beta-blocker". He explained that as a result he had gone to see his GP about it, who "said this could be making me a bit dizzy so he reduced the bisoprolol". R21 said that whenever she had been given a new medicine she had "read all through the script in it and it tells you all the possible side effects" and pointed out that it "frightens the life out of you, well it would if you were that sort of person". She said that she had "developed a really rotten cough and I'd also heard that ramipril can do it" so had "read the whole piece of paper that's in all these tablets and it said that it could be a side effect of the ramipril" before going to see her GP about it. R28 said that "medicines nowadays they come with a note with them don't they and they're very informative" and pointed out that "I like the nitty gritty bits", especially about side effects and added "I have to know and if I can't find anything, I'll have a look on the web". It seemed that a particular reason for this was because he had found that he was "allergic" to certain medicines, such as nicorandil, which had caused a "severe allergic

reaction” where his “face went all red, all round the eyes and everything, lost all my hair” and his “arms was dead red and everything you know”. R23 said that he used to get “a bit bloody minded some days and think sod the tablets you know, but you know I’m used to it and I can pop them in without any problem nowadays”, although he remained concerned about the potential for medicines to cause side effects. A particular reason for this was that aspirin “didn’t half play hell with my stomach”, which had prompted a visit to his GP. He said “when things are prescribed the doctor always says what he’s prescribing it for and I always ask if there are any side effects” and added:

“One thing I do when I get a tablet I always read the instructions and I know what the side effects are, before you know where you are you’re thinking you’ve got all the side effects, that’s a problem but you know I know what they’re supposed to do.” (R23)

R22 said that he had not experienced any side effects from his medicines but had been concerned that he might gain weight by taking atenolol and had asked his GP about it:

“That one, that atenolol, I did ask him about that ‘cos I heard a bit about them, about putting on weight and all that. I asked the doctor about it, well I’ve heard different people say about these beta-blockers make you put weight on and he said oh you won’t put a lot of weight on with them, you’re only on a small dosage. He said they’ll not affect you.” (R22)

Two patients expressed disquiet about taking medicines because of the potential for them to cause long-term problems. R27 talked about medicines causing “long-term

problems” such as “kidney problems” because “I mean not all the drugs and the combinations of are known over long periods, are they” and said that finding out about this had been:

“...a gradual accumulation of knowledge of necessity and then questioning too, you know, long term effects but fortunately I’ve always been with good GP practices, periodic testing to see that no kidney problems have arisen because of these medications took over a long period. So that’s something I’m aware of now, so it’s just part and parcel, the knowledge that you’ve built up.” (R27)

R24 talked about having been concerned that atenolol might cause “diabetes and all sorts” if he continued to take it:

“I mentioned atenolol when I saw the surgeon last week, I mentioned that I’d read in the papers and seen on the television they reckoned that it was bad for you; it’s been proved to cause diabetes and all sorts. They were going to change it and he said well no it’s perfectly alright so he left it like that. Yes he said it was one of the best tablets.” (R24)

In contrast, four patients did not seem to express any disquiet about their medicines. R19 and R20 both said that that had not had any problems or side effects with their medicines and R20 pointed out that he had not asked his GP any medicines-related questions so tended to be “in and out in about two minutes”. R25 said “if I thought

taking this medicine was causing me problems in some way then I'd go and question it with the GP" but pointed out that he had not experienced any side effects and added:

"I must admit I've never really questioned the necessity to take the medicines that have been prescribed for me; they know what they're talking about, they know what they are doing and that it's necessary."

(R25)

R26 said that his wife "worries about tablets" but added "I'm anything for a quiet life and she'll say to me why do you take this tablet, do you need it and I say well the doctor said, you know". He added, "I just take it for granted that the tablets they prescribe must be the right ones because they know what they're talking about" and that if "the doctor says to me, you need that tablet, I just take it for granted the man's right".

7.6.3 Explaining why the medicines had been prescribed

When patients were asked what heart-related medicines they were currently taking, nine patients seemed to have difficulty remembering the names of all of their medicines. Of the four patients (R17, R18, R22 and R24) who appeared to know all of their current medicines, three of them (R17, R22 and R24) referred to a list. From what patients said, at least eight patients appeared to be taking aspirin, at least three patients appeared to be taking warfarin or clopidogrel instead and at least ten patients appeared to be taking a statin. Establishing whether patients were taking beta-blockers, ACE inhibitors or other heart-related medicines (e.g. nitrates or calcium channel blockers) was particularly difficult, since these seemed to be commonly referred to as "blood pressure tablets", although it appeared that at least six patients were taking a beta-blocker, at

least three patients were taking an ACE inhibitor and at least three patients were taking a nitrate or a calcium channel blocker. In addition, at least two patients were taking a “water tablet”, although they did not specify the name of the medicine.

When patients were asked why they thought their heart-related medicines had been prescribed, nine patients responded by talking mainly about the medicines reducing their risk of having a heart attack, dying or their arteries getting “furred up” or “blocked” again. Of these patients, four (R18, R21, R27 and R28) explained how specific medicines (but only one or two medicines, rather than all of them) could reduce their risk, although only R21 and R27 seemed to relate this to what they thought had caused their CHD. The other five of these nine patients talked about their medicines in general reducing their risk without explaining how any specific medicine might do this or relating this risk reduction to what they thought had been the cause of their CHD. Of the remaining four patients, R16 talked about some of his medicines controlling or reducing his angina but did not relate how he thought his other medicines worked to his own circumstances, whilst three patients (R19, R22 and R26) talked about “needing” the medicines but did not give a specific reason. This suggested that the patients, in a similar way to the heart attack patients (section 5.3.3), may have found it problematic to relate explanations about how the medicines work to their own circumstances and may have taken explanations in the information they were given at face value.

Of the four patients who talked about how specific medicines could reduce their risk and related that to their own circumstances, R21 talked about taking a beta-blocker to reduce her blood pressure and that she took it to reduce her risk of having a heart attack or being “ill” again, as is shown in the quote from her in section 7.6.1. As was

discussed in section 7.5.1, high blood pressure seemed to be the only possible cause of her CHD she could think of. R27 said “I’m one of those people whose body produces more cholesterol, so that’s why I have to have that [statin]”. He related the cholesterol-lowering effect of taking a statin to his own circumstances by explaining that high cholesterol had caused “furring up” in his arteries and increased his risk of a “bit of cholesterol” causing a “block” (i.e. a heart attack):

“It’s furring up the arteries, narrowing the space in which the heart has to pump that blood. Therefore it increases the pressure and also there’s a danger that bits of cholesterol will fly off and block.” (R27)

He related this to heredity (or as he put it, a “familiar history”) probably causing his CHD (see section 7.5.1) by saying “my liver produces too much cholesterol and that’s probably what the familiar problem would be”. R28 did not relate what he thought had been the cause of his CHD (see section 7.5.1), to his explanation for how medicines could reduce his risk, since he said about having high cholesterol “I suppose it was at some stage, my arteries weren’t clogged I know that”. He explained that taking a statin would help keep the veins bypassing his “collapsed” coronary arteries “clear”, the significance of which was that these veins were “only thin”, unlike his “big, wide” arteries that had “collapsed” and were subsequently at greater risk of getting “clogged”:

“Well that’s why you’re still taking the pills, this is sort of preventing it you know like the statin, you know stops your arteries from furring up and ‘cos you’ve got these little two veins in there. Well actually, one from here [leg] and one from your ribs, your inter-costal muscles, where the veins go and

they took one from there and they're only thin so you've got to keep them clear haven't you, hence the statin." (R28)

Similarly, R18 (who thought that heredity may have been the cause) said about aspirin "they say it helps a great deal in reducing the risk of clotting which is obviously the major cause of heart attacks" and explained how taking a statin could reduce his risk by saying:

"The statins generally are good not just in lowering cholesterol but improving the arteries anyway, which also evidently the statins tend to not just prevent the bad cholesterol build up but they also tend to soften them. Evidently with heart disease your artery gets calcified and evidently it softens them so that it can make things a lot easier for your heart basically." (R18)

Of the five patients who talked about their medicines in general reducing their risk without explaining how any specific medicine might do this or relating this risk reduction to a possible cause of their CHD, R24 said about the reason for taking the medicines:

"It's as a precaution, I thought I wouldn't have to take any tablets but when you read through this you know to keep it open and to keep the heart working." (R24)

R17 said that he thought taking the medicines would help prevent "the arteries" from getting "blocked" but did not say how he thought they might do this, whilst R20 said

about taking medicines “it keeps me living” and “it keeps me from being ill”. R25 said that “if you didn’t take them you’d probably suffer” and that:

“I just assumed you know that when you’ve had a major operation on any organ of the body that you’re far more vulnerable to things going wrong than you were before the operation and it’s necessary to take them to control things so that you know there’s no strain put on that organ unnecessarily. Again it’s part of my faith in the medical profession I suppose, if they say you need it, you need it.” (R25)

R23 said that he took “mainly blood pressure tablets” and “the cholesterol tablet” and “another couple for the heart” but added:

“I really don’t know whether it’s to help increase the blood flow to and from the heart by giving you these tablets, to avoid any other narrowing and problems in that direction I don’t know, they [doctors] must know what they’re doing...I sometimes sit and think well are they doing me any good or what on earth are they doing? I leave it to the doctors to prescribe the tablets, they wouldn’t do it if they didn’t think it wasn’t going to improve one’s health would they, I would think.” (R23)

Rather than talking about medicines reducing risk, R16 talked about medicines controlling or reducing his angina, which seemed to be because he continued to get angina after having the bypass operation (see section 7.3.2). He said “I take these medicines because I need them you know” and added “I don’t want the pain back and

that means I've got to continue to take the tablets". He talked about taking other heart-related medicines (for example, to reduce his "heart rate") as well as those to reduce his angina but did not relate the way that these other medicines worked to his own circumstances. In comparison, R27 (who also had a long history of angina) had not experienced any angina after his operation (section 7.3.2) and whilst he talked about taking medicines to control his angina before his operation, these medicines had since been stopped and he only talked about his current medicines in terms of risk reduction.

In contrast, three patients (R19, R22 and R26) talked about "needing" the medicines but did not give a specific reason and all three indicated that they relied on their doctor to know how the medicines work. R26 said "you take it for granted that the tablets they prescribe are the right ones because they know what they're talking about", R19 said about his doctor knowing "what they was there for like", whilst R22 said "I mean if they've given you these tablets, they've given you them for a reason I think".

7.7 Chapter summary

It seemed that having CABG surgery had considerably lessened the impact of CHD on patients' lives. They seemed to have made the decision to have the operation after having assessed the risks of serious CHD-related events happening (e.g. heart attack or death) if they did *not* have it. Afterwards, it seemed that they no longer saw themselves as being at imminent risk and only talked about their longer-term risk of having further heart-related problems. In contrast to the heart attack patients, none of them appeared to be fearful about the risk of having a serious CHD-related event.

All of the patients talked about aspects of lifestyle causing CHD but only two patients appeared to think that their lifestyle had caused their CHD, although many patients seemed uncertain about the cause. Six patients did not change their lifestyle around the time of the CR programme, four patients did not maintain lifestyle changes made after having their operation, whereas three patients made and maintained lifestyle changes after their operation. However, their approach to lifestyle risk reduction appeared to follow from their perspectives on their risk of experiencing further CHD-related events. As such, the aspects of lifestyle that patients modified and maintained tended to have been those that they perceived to have been likely causes of their CHD requiring CABG surgery.

All of the patients indicated that they were taking their medicines by either saying that they were taking them, by having a strategy to remember to take them, by not intentionally missing doses or by tolerating or seeking medical advice about side effects, rather than just stopping the medicines responsible. However, nine patients expressed disquiet about medicines because of side effects or the potential for long-term problems. Nine patients talked about medicines reducing their risk of having a heart attack, dying or their arteries getting “furred up” again. However it seemed that patients may have found it problematic to relate explanations about how the medicines work to their own circumstances, in a similar way to the heart attack patients. The significance of these findings is now discussed in the final chapter of this thesis.

Chapter Eight

Discussion

8.1 Introduction

The purpose of this chapter is to discuss four main issues: In section 8.2 the significance of the findings of the study and how these relate to the research question are discussed. Consideration is then given to how these findings relate to the literature, especially the literature on patients' perspectives on CHD that was discussed in chapter two (sections 8.3 and 8.4); The implications of the findings for professional practice and the improvement of CR programmes (section 8.5) is then discussed. Finally, issues concerned with the practical application of reflexivity in the study are considered (section 8.6).

8.2 The significance of the findings of the study

As discussed in section 3.1.1, the overall aim of the study was to explore CR patients' perspectives on CHD and its treatment (i.e. lifestyle modification and medicines) using a qualitative approach (the rationale for which is discussed in section 3.2.1). This arose from a research interest in CR patients' perspectives on the use of medicines in relation to their perspectives on lifestyle modification and CHD, which remains under-reported in the literature (sections 2.4.3 and 3.3.1). An important theme that emerged from the initial interview stage data concerned how patients' perspectives on their risk of experiencing further CHD-related events may be related to their perspectives on lifestyle modification and use of medicines. The significance of this was that their perspectives on risk seemed to be linked to their fear of having another heart attack. In

conjunction with the findings from the literature (sections 2.4.2, 2.4.3 and 3.3.1), this suggested that if they felt less fearful over time, their perspectives on risk, and in turn, treatment may also change.

As discussed in section 6.3.2, the findings from the second interview stage of the study (approximately a year after their heart attack) indicated that patients tended to be much less fearful of having another heart attack than they had initially been, although residual fears often appeared to remain. There also seemed to have been changes in their perspectives on risk. Unlike before, patients tended to now assess their risk in terms of what they had been told about the damage done to their heart or how their heart was functioning (section 6.3.3), as well as in relation to what they thought had been the likely causes of their heart attack. Furthermore, it seemed that there was a tendency for subtle changes to have occurred in patients' perceptions of the likely causes, although their perceptions were still broadly similar to what they had said in the initial interview (section 6.3.1). These changes involved now citing non-lifestyle factors (e.g. bad luck) as being more likely causes than certain (but not all) of the aspects of lifestyle that they had formerly cited as likely causes. Some causes formerly cited were now considered to be less likely causes.

By the time of the initial interviews many patients had made several lifestyle changes, including some aspects of their lifestyle that they had not cited as causes of their heart attack (table 2, section 5.2). It seemed that fear of having another heart attack if these changes were not made, or at least a keen desire not to have another heart attack, had been an important influence on their decision to initially make these lifestyle changes (as discussed in section 6.3). By the time of the second interviews, five (half) of the

patients did not seem to have maintained all of their initial lifestyle changes but appeared to now place less value on maintaining these changes, at least in part, because they viewed these aspects of lifestyle as being less likely causes of their heart attack than at the time of the initial interview (section 6.4). In contrast, three patients who had maintained their lifestyle changes talked about experiencing benefits and the value that they placed on maintaining these changes did not seem to have changed.

Despite the tendency for patients' perspectives on their risk of having another heart attack and their perspectives on lifestyle modification to have changed, there did not seem to have been any changes in their perspectives on taking medicines between the initial and second set of interviews (section 6.5). All of the patients indicated that they were still taking their medicines and, when asked, talked about having no intention of deliberately stopping them. At the same time, many patients expressed a sense of disquiet about taking their medicines in the initial interview (section 5.3.2) and in the second interview (section 6.5.1). In addition, it seemed that whilst patients mainly viewed their medicines in terms of reducing the risk of having another heart attack, they tended to remain uncertain about *how* the medicines reduced *their* risk and whether this related to their perceived causes of their heart attack. In short, the findings suggested that patients' fear of having another heart attack significantly reduced over time and this seemed to be associated with changes in their perspectives on the risk of having another heart attack and lifestyle modification but not medicines.

The third stage of the study focused on one deviant case in the initial sample (R16) who had not had a heart attack. Rather, he had had coronary artery bypass grafting (CABG) surgery resulting from a long history of angina. As discussed in sections 3.3.1 and 7.1,

there appeared to be three issues that emerged from the interviews with R16, which when considered together suggested that his perspectives on CHD and its treatment were different to the heart attack patients (including R8 who went on to need a CABG after having a heart attack) and that this may have been because he had not had a heart attack. Firstly, he talked about his risk of having a serious CHD-related event (i.e. heart attack or death) being a matter of bad luck or chance and said that he was not worried about it. Secondly, whilst he thought that smoking was a likely cause of his CHD, he had stopped smoking twenty-five years ago. He did not seem to think that any other aspects of his lifestyle had been likely causes and subsequently did not seem to have maintained lifestyle changes that he made around the time of attending CR. Thirdly, he talked about his medicines being prescribed to control his angina, rather than to reduce the risk of serious CHD-related events. In addition, his perspectives on the risk of experiencing further CHD-related events did not seem to have changed by the time of the second interview. Hence, a need for a set of interviews with other CR patients who had not had a heart attack to explore this further.

The findings from the third stage of the study suggested similarities between R16's perspectives and other CABG surgery patients who had not had a heart attack. The CABG surgery patients did not see themselves as being at imminent risk of further CHD-related events happening and were not fearful about it because they had had their operation, which was why they only talked about their longer-term risk when asked if they thought they might experience further CHD-related events (section 7.4.2). Patients also tended to talk about bad luck or chance determining whether they experienced further CHD-related events. With the exception of R22, none of the other patients seemed to think that aspects of their lifestyle had been likely causes of their CHD

(section 7.4.3) and nine patients (in addition to R16) had either not made lifestyle changes or had not maintained initial changes that they had made around the time of attending CR (section 7.5). However, in contrast to R16's perspectives, the other CABG surgery patients mainly talked about their medicines being prescribed to help prevent further CHD-related events (section 7.6.3). Comparison of the data suggested that R16's perspectives on why he thought the medicines had been prescribed was more likely to be related to his long history of angina and that (unlike the other CABG surgery patients) he continued to experience angina after having his operation, than being related to not having a heart attack. As such, he remained a deviant case on this point.

Furthermore, it seemed that the CABG surgery patients' perspectives on the risk of further CHD-related events and treatment were extremely similar to the heart attack patients' perspectives at the second stage interviews, such that there seemed to be no major differences between their perspectives. This was suggested by the following similarities. Both the heart attack patients (by the time of the second interviews) and the CABG surgery patients seemed to have assessed their risks of experiencing further CHD-related events and did not seem to view themselves as being at imminent risk (sections 6.3.3 and 7.4.2). Both groups of patients were aware that heart attacks or CHD requiring CABG surgery could be caused by aspects of lifestyle as well as non-lifestyle related factors (e.g. heredity), although the CABG surgery patients did not cite stress as a likely cause, unlike some of the heart attack patients (section 6.3.1 c.f. section 7.4.3). Most patients seemed to remain uncertain about the likely causes of either their heart attack or CHD requiring CABG surgery (sections 6.3.1 and 7.4.3). Both groups of patients tended to have assessed their risk of experiencing further CHD-related events in terms of what they perceived to have been the likely causes (sections

6.3.1 and 7.4.3) and what they had been told about the damage done to their heart or how their heart was functioning (sections 6.3.3 and 7.4.2). In addition, both groups of patients often referred to chance or bad luck also determining whether or not they actually experienced a further CHD-related event (sections 6.3.4 and 7.4.2). Having said this, the heart attack patients spoke about personal responsibility for risk reduction as well as bad luck or chance (section 6.3.4), whereas few of the CABG surgery patients spoke in terms of personal responsibility when talking about whether they thought they might experience further CHD-related events.

The similarities between the two groups of patients' perspectives on treatment were seen in relation to lifestyle modification and particularly medicines. In general, both groups of patients seemed to adopt an approach to lifestyle modification that followed from their perspectives on their risk of experiencing further CHD-related events. As such, the aspects of lifestyle that patients modified and maintained tended to have been those that they perceived to have been likely causes of either their heart attack or CHD requiring CABG surgery. Conversely, aspects of lifestyle that patients did not seem to perceive as likely causes did not tend to have been changed or were initially changed but did not tend to have been maintained (sections 6.4 and 7.5). All of the patients in both groups indicated that they were taking their heart-related medicines and demonstrated this in one or more of four ways (sections 6.5.1 and 7.6.1): by talking about being prepared to take them; by having a strategy to remember to take them; by showing that where doses had not been taken as usual, this had been unintentional; and by tolerating or seeking medical advice about side effects, rather than simply discontinuing the medicines thought to be responsible. Despite this, many patients in both groups expressed a sense of disquiet about taking medicines (sections 6.5.1 and

7.6.2), which often concerned the potential for medicines to cause harm (e.g. side effects or the potential for long-term problems). Many patients in both groups seemed to have difficulty remembering the names of all of their medicines but mainly talked about them being prescribed to help prevent further CHD-related events (except R16, as discussed). Most patients in both groups did not talk about how the perceived causes of either their heart attack or CHD requiring CABG surgery related to how they thought that individual medicines could help prevent further CHD-related events and those who did seemed to have found this problematic. This suggested that patients in both groups may have taken explanations in the medicines-related information they were given at face value without necessarily considering how this related to their own circumstances.

In short, the findings of the third stage of the study did not support the idea that R16's perspectives were different to those of the heart attack patients because he had not had a heart attack. Rather, the findings suggested that when the heart attack patients' fear of having another heart attack had subsided there were few, if indeed any, differences between their perspectives and the CABG surgery patients' perspectives on the risk of experiencing further CHD-related events, lifestyle modification and medicines. The significance of this finding is that fear of having another heart attack may heighten heart attack patients' perception of risk and influence the choices they make about lifestyle modification but only in the short term. In the longer-term, CR patients' perspectives on their risk of experiencing further CHD-related events and treatment for CHD are likely to be similar, irrespective of whether or not they have had a heart attack. Discussion now moves on to consider the significance of these findings in relation to the literature. This begins with the impact of either having a heart attack or CHD requiring CABG surgery and the risk of experiencing further CHD-related events.

8.3 Understanding patients' perspectives on CHD

8.3.1 The impact of having a heart attack or CHD requiring CABG surgery

The profoundly disruptive effect that serious illness often has on people, such as having a heart attack or CHD of such severity that requires CABG surgery, has been described as “biographical disruption” by Bury (1982). Many studies have explored the disruptive effect that either having a heart attack or CABG surgery has on people (as discussed in sections 2.4.1 and 2.4.2) and there are several points of similarity between the findings of this study and other studies. As discussed in section 4.3, the experience of having a heart attack for many patients seemed to have been frightening and distressing, which perhaps not surprisingly has been widely reported in the literature (e.g. Bergman & Bertero 2003, East *et al* 2004, Gassner *et al* 2002, Jensen & Petersson 2003, Johnson & Morse 1990, Lisk & Grau 1999, White *et al* 2007, Wiles 1998, Wiles & Kinmonth 2001). The initial process of seeking medical care seems to have been characterised by: firstly, patients not initially recognising symptoms, at least in part because they had not been doing anything unusual (section 4.3.1); and secondly, seeking advice about symptoms from partners or colleagues (section 4.3.2). This is in common with other studies that have shown that patients tend to go through a process of making sense of and responding to their symptoms before seeking medical care (Clark 2001, Johnson & Morse 1990, Ruston *et al* 1998).

This study found that the process of recovery from a heart attack seemed to have been characterised by: fear of having another heart attack, especially that it might be fatal; feeling tired all of the time or becoming easily fatigued; wanting to get back to a previous level of functioning; and finding it difficult to take in all of the information given (section 4.5). Over the subsequent nine months after the initial interview (i.e. at

approximately a year after discharge from hospital) the impact of having a heart attack appeared to considerably lessen for most but not all of the patients (section 6.2.1). In particular, patients tended to be much less fearful of having another heart attack, although residual fears often appeared to remain (section 6.3.2). These findings are broadly in common with Johnson & Morse's (1990) findings, which were encapsulated in their detailed four-stage model of the process of adjustment after a heart attack, which was discussed in section 2.4.2. Indeed, many other studies of qualitative studies of heart attack survivors have also described the fear, feelings of uncertainty and emotional lability that patients often experience, especially in the first few weeks after discharge from hospital (e.g. East *et al* 2004, Gambling 2003, Jackson *et al* 2000, Jensen & Petersson 2003, White *et al* 2007, Wiles 1998). Similarly, many studies have shown that fear and anxiety experienced by heart attack survivors reduced over time if there was no recurrence of CHD-related events (e.g. Gambling 2003, Jackson *et al* 2000, Lisk & Grau 1999, Wiles 1998). In short, this study as well as numerous other studies suggests that recovery after a heart attack involves a range of physical and psychological issues, which include coming to terms with having had a heart attack and negotiating an uncertain process of adjustment.

In comparison to the experience of having a heart attack, the experience of having CHD, seeking medical care and having CABG surgery typically occurred over a longer period of time (section 7.3.1). It also did not seem to have been associated with the same degree of fear and distress that the heart attack patients tended to experience (section 7.3.1). Having said this, it seemed that while patients were waiting for their operation, many of them were very aware of being at risk of experiencing a serious CHD-related event, such as a heart attack or death (section 7.4.1). After having the

operation it seemed that the impact of having CHD had considerably lessened for all except one of the patients; very few of them continued to experience symptoms (e.g. breathlessness or angina) and those that did talked about their symptoms being much less severe or frequent (section 7.3.2). However, experiencing post-operative physical problems (e.g. discomfort at the chest scar site or it taking a long time for leg wounds to heal) seemed to be quite common (section 7.3.2). These findings are broadly similar to other studies of patients who have had CABG surgery, particularly that patients were keenly aware of being at risk prior to surgery (Radley 1996, Lindsay *et al* 2000), that patients appeared to judge their state of health by the presence or absence of symptoms (Lindsay *et al* 2000, Plach & Stevens 2001) and that post-operative physical problems seem to be quite common (Hawthorn 1993, Treloar 1997).

One finding that was common to both the heart attack patients (at the time of the second interview) and the patients with CHD requiring CABG surgery was that none of them had become involved in any patient groups since attending the CR programme (sections 6.2.2 and 7.3.3). This was because patients had chosen not to, rather than that they had been unaware that they could, since they were given information about local patient groups when they attended the CR programme. The reasons patients gave for not attending a patient group indicated that they did not see that it was relevant to them or necessary, especially as they had attended the CR programme and their health had since improved. Indeed, some patients pointed out that they had wanted to put their illness behind them and get on with their lives, rather than continuing to focus on it (section 7.3.3). This finding does not appear to have been reported in previous studies of CHD patients. However, Gambling (2003) recruited patients for her study of the informational needs of CHD patients from a CHD self-help group that had a

membership of over two hundred patients. The members had angina or had previously had a heart attack but it was not reported whether or not any of them had attended a CR programme. She found that the timing of information provided to patients was important, since they demonstrated a readiness for information at different points in the recovery process. In this study, some heart attack patients talked about being overwhelmed by the information they had received (section 4.5.4), although this was at the time of the initial interview and patients did not talk about this in the second series of interviews. Further research seems warranted to explore perspectives on patient groups amongst CHD patients who have not attended a CR programme.

8.3.2 Explaining the cause and assessing the risk of experiencing further CHD-related events

It seemed that a particular concern that arose for patients from the biographical disruption caused by either having a heart attack or CHD requiring CABG surgery was in trying to explain why it had happened, which is well established in the literature (e.g. Bergman and Bertero 2003, Clark 2003, Fleury *et al* 1995, Jensen & Petersson 2003, Johnson & Morse 1990, Murray *et al* 2000, Sutherland and Jensen 2000, Tobin 2000, Treloar 1997, Wiles 1998). Indeed, this seems to be an important concern for people who have suffered any serious illness (Bury 1982, Frank 1995, Hyden 1997, Williams 1984). More generally, as discussed in section 2.3, Davison and colleagues (1991) described the everyday process of lay theorising on the distribution of ill health as “lay epidemiology”, which Lupton and Chapman (1995) similarly described as an “interpretive repertoire of risk”. This is a sophisticated process that involves critical assessment of the extent of preventability or inevitability in other people’s illness and death as well as having particular relevance to personal illness. As a result, people may

challenge official explanations and be sceptical about official health advice (Davison 1989, Davison *et al* 1992, Lupton & Chapman 1995). In relation to CHD, this process provides answers to why it happened and why at that particular time but also allows for assessment of personal risk, which concerns the risk of experiencing further CHD-related events for patients who have either had a heart attack or CHD requiring CABG surgery (French *et al* 2004, Davison *et al* 1991, 1992). In contrast, the “official” explanation that CHD occurs as a consequence of risk factors attempts to answer both questions at once (Davison *et al* 1991).

Numerous studies have found that people are aware of various “known” risk factors for CHD, not all of which are related to lifestyle (e.g. Davison *et al* 1991, 1992, French *et al* 2005). This is supported by epidemiological evidence that acknowledges a variety of non-behavioural risk factors for CHD and indicates that the prevalence of lifestyle risk factors alone does not account for the incidence of CHD (Ebrahim *et al* 2004, Masia *et al* 1998, Terris 1996, Vartiainen *et al* 1998). Patients do not tend to dispute whether or not “known” factors are indeed risk factors, even if they do dispute that any of these factors caused any particular case of CHD, which challenges the notion of lay knowledge of illness being clearly distinct from “expert” knowledge (Davison *et al* 1991). It is also recognised that having risk factors only increases the likelihood of getting CHD but that this is not guaranteed to result in CHD; not everybody who engages in risky behaviours will suffer from CHD and vice versa. This is likely to be explained as being a matter of bad luck, chance or fate (Davison *et al* 1991, 1992). In this study (section 4.4.1) several patients talked about people who they had not considered to be at risk of CHD but had nonetheless suffered a heart attack, whilst R12 talked about her mother

as an example of someone who she considered to be at risk but had not had a heart attack.

In patients' explanations about the likely causes of either their heart attack or CHD requiring CABG surgery, lifestyle causes were cited as well as non-lifestyle causes such as heredity (sections 4.4.1, 6.3.1 and 7.4.3). However, most patients seemed uncertain about whether any of these factors had been a cause and often talked about it being a matter of bad luck or chance (sections 4.4.2, 6.3.1 and 7.4.3). Indeed, many patients seemed more certain about what had *not* been the cause, since they discounted possible factors (especially aspects of their lifestyle) when talking about what they thought had been the likely causes (sections 4.4.2, 6.3.1 and 7.4.3). Other studies have found that patients cited both lifestyle factors and non-lifestyle factors such as heredity as likely causes of their CHD (e.g. French *et al* 2005, Jensen & Petersson 2003, Tobin 2000, Treloar 1997, Wiles 1998). On the other hand, some studies reported that all of the patients thought that CHD was caused by lifestyle factors (e.g. Attebring *et al* 2005, Johnson & Morse 1990, Sutherland & Jensen 2000), even if they were unable to find a lifestyle cause of their own CHD (Johnson & Morse 1990). Studies have also reported that some patients, especially those who were unable to find a lifestyle explanation, thought that bad luck, chance or fate had been the cause of their CHD (e.g. Bergman & Bertero 2003, Wiles 1998). As such, it appears to be well established that explaining causality is a sophisticated process and a variety of factors may be cited by patients as possible causes of either their heart attack or CHD requiring CABG surgery, which may include aspects of lifestyle and non-lifestyle factors such as heredity or bad luck. Where this study appears to differ from other studies is in showing the extent to which patients seemed to remain uncertain about what had been

the cause of either their heart attack or CHD that required CABG surgery, even where likely causes were cited.

Uncertainty about whether their perceived lifestyle causes might, if not modified, lead to further CHD-related events happening and an awareness of the apparently random occurrence of CHD, especially heart attacks, subsequently seemed to characterise patients' assessment of their risk of experiencing further CHD-related events (sections 6.3.1 and 7.4.2). Yet information that patients had been told (and had seemed keen to know) that indicated that there had been little permanent damage done to their heart or that their heart was apparently functioning normally seems to have been seen as being more certain. Indeed, it seemed that this information had more influence than explanations about the likely causes on patients' view of themselves as not being at imminent risk of experiencing further CHD-related events and in seeing their possible risk as being longer-term (sections 6.3.3 and 7.4.2). It seemed that this applied equally to the heart attack patients (around the time of the second interview, i.e. a year after their heart attack) and the patients who had not had a heart attack but had had CABG surgery, including those patients who had been told that they still had lesions in their coronary arteries but of less severity than those that had been bypassed (section 7.4.2).

This finding that patients may incorporate specific medical information about the state of their coronary arteries discovered during angiography, information about how their heart was functioning based on electrocardiogram results or physical measurements such as heart rate or blood pressure into their assessments of their risk of experiencing further CHD-related events does not appear to have been reported in the literature before. To a certain extent this may be because studies of patients' experiences of either having a

heart attack or CABG surgery (section 2.4.2) have tended to focus on the nature of the experience, the process of recovery or patients' perspectives on their recovery, rather than on patients' perspectives on their risk of experiencing further CHD-related events (e.g. Bergman & Bertero 2001, 2003, East *et al* 2004, Fleury *et al* 1995, Ford 1989, Jensen & Petersson 2003, Johnson & Morse 1990, Kerr & Fothergill-Bourbonnais 2002, LaCharity 1997, Levy 1981, Lisk & Grau 1999, Tobin 2000, Treloar 1997). Subsequently, published reports arising from these studies have not presented detailed insights into patients' perspectives on their risk of experiencing further CHD-related events. This is especially so for studies of heart attack patients, although (as was similarly found in this study) studies of CABG patients have reported that patients did not view themselves to be at risk because they had had the operation (Lindsay *et al* 2000, Lisk & Grau 1999). Furthermore, studies of lay perspectives on the risk of CHD (section 2.3) have often been concerned with specific groups of lay people who did not have CHD (e.g. Farooqi *et al* 2000, Meillier *et al* 1996, Narevic & Schoenberg 2002, Nic Gabhainn *et al* 1999, Ritchie *et al* 1994) or people who were considered to be at increased risk but did not actually have CHD (e.g. Angus *et al* 2005, Bach Nielsen *et al* 2005, Durack-Bown *et al* 2003, Hollman *et al* 2004, Hunt *et al* 2001, Senior *et al* 2002, Tolmie *et al* 2003, Troein *et al* 1997). As such, it cannot be assumed that these findings can be unproblematically applied to patients with CHD. Criticism about there being limited research on how patients with CHD assess their risk of experiencing further CHD-related events (Wiles 1998) still appears to be pertinent and the focus of work that has been done has remained on patients' explanations about the cause of their CHD (e.g. French *et al* 2005, Gambling 2003, Wiles 1998, Wiles & Kinmonth 2001).

In this study it has been shown that patients did consider aspects of their lifestyle that they perceived to be likely lifestyle causes, as well as likely non-lifestyle causes (particularly bad luck or chance) in sophisticated yet uncertain assessments of their future risk, but that this was not the only way that risk appeared to be assessed. Fear of recurrence may have heightened heart attack patients' perception that they would have another heart attack, since it *had* happened and *could* happen again at any time without warning, although this appeared to have been a relatively short-term effect, as discussed in section 8.2. As their fear of recurrence reduced, heart attack patients tended to assess their risk of experiencing further CHD-related events on the basis of their perceptions about the likely causes, combined with information about heart damage or heart function. At that point the heart attack patients appeared to view their risk in the same way as CR patients who had not had a heart attack but had had CHD that required CABG surgery. With these issues in mind, the discussion now moves on to patients' perspectives on lifestyle modification and taking medicines.

8.4 Understanding patients' perspectives on lifestyle modification and taking medicines

8.4.1 Patients' approach to lifestyle modification

As discussed in section 2.4.3, it is well established in the literature that patients who have either had a heart attack or CHD requiring CABG surgery often experience difficulty in making and maintaining lifestyle changes (Bergman & Bertero 2001, Boutin-Foster 2005, Condon & McCarthy 2006, Gambling 2003, Karner et al 2005, LaCharity 1997, 1999, Plach & Stevens 2001, Sjöström-Strand & Fridlund 2007, Thomas 1994, Tobin 2000, Treloar 1997). Similarly, Crawford (2000, 2004) has depicted lifestyle

modification as a “perpetual struggle”, whilst Pill and Stott (1985) pointed out that lifestyle modification requires a continual effort rather than one or two “big efforts”. This study supports this by providing detailed accounts (sections 5.2, 6.4 and 7.5) of what making lifestyle changes meant for patients and showing that patients did not always find changing aspects of their lifestyle easy: For example, R10 did not find it easy to stop smoking (section 5.2.1); R2 and R15 found doing enough exercise difficult (section 5.2.2); R1 (section 5.2.3) and R2 (section 6.4) found losing weight difficult; R15 found reducing job-related stress difficult (sections 5.2.3 and 6.4); and, R27 and R28 found doing exercises difficult.

The literature (section 2.4.3) also establishes that some patients, but typically not all patients, make and maintain some lifestyle changes but not necessarily all of the changes recommended (Bergman & Bertero 2001, East *et al* 2004, Ford 1989, Gambling 2003, Jensen & Petersson 2003, Roebuck *et al* 2001, Tobin 2000, Tolmie *et al* 2006, Wiles 1998, Wiles & Kinmonth 2001). This finding is supported by numerous quantitative studies (e.g. Evans *et al* 2005, Reimer *et al* 2006). In this study (as discussed in section 8.2) both groups of patients seemed to adopt an approach to lifestyle modification that followed from their perspectives on their risk of experiencing further CHD-related events. As such, the aspects of lifestyle that patients modified and maintained tended to have been those that were perceived to have been likely causes of either their heart attack or CHD requiring CABG surgery. Conversely, aspects of lifestyle that patients did not seem to perceive as likely causes did not tend to have been changed, or were initially changed but did not tend to have been maintained (sections 6.4 and 7.5). This supports those studies of heart attack patients that found that decisions about lifestyle changes were influenced by how patients made sense of

their heart attack (Jensen & Petersson 2003, Johnson & Morse 1990, MacInnes 2005, Ononeze *et al* 2006, Thomas 1994, Wiles 1998, Wiles & Kinmonth 2001). This study also supports studies that found that patients viewed lifestyle modification in terms of reducing the risk of experiencing further CHD-related events (East *et al* 2004, LaCharity 1999, Jensen & Petersson 2003, Scherck 1992, Treloar 1997), rather than studies that found that patients viewed lifestyle modification in terms of leading to improvements in their health or achieving recovery (Berman & Bertero 2001, Johnson & Morse 1990, Tobin 2000, Wiles 1998, Wiles & Kinmonth 2001). It seemed that the only recommendations that patients in this study saw as leading to recovery were those that concerned resumption of normal activities in the first six weeks after discharge from hospital, before they attended the CR programme (section 5.2.2).

In contrast to studies that found that heart attack patients tended to have low motivation towards long-term lifestyle change (Wiles 1998, Wiles & Kinmonth 2001), the findings of this study suggested that heart attack patients tended to remain committed to lifestyle changes, but only to aspects of lifestyle that continued to be perceived as likely causes of their heart attack. Consequently, patients who did not seem to perceive that any aspects of their lifestyle had been likely causes of their heart attack did not appear to have maintained any lifestyle changes (section 6.4), as was found in other studies (Jensen & Petersson 2003, Johnson & Morse 1990, MacInnes 2005, Thomas 1994). This also seemed to apply to the CR patients who did not have a heart attack but had had CABG surgery (section 7.5), which does not appear to have been reported before. The value of this study is in providing longitudinal data about heart attack patients' perspectives on lifestyle modification, unlike most studies, and that this goes significantly beyond the early few months after a heart attack (i.e. around the time of

completing the CR programme), as was done in the only study that did provide longitudinal data (Wiles 1998, Wiles & Kinmonth 2001). Subsequently, this study is able to show that whilst heart attack patients' perspectives on lifestyle modification did seem to change over this longer period of time (i.e. not all lifestyle changes were maintained), this appeared to be consistent with changes in their perspectives on risk. In turn, this seemed to be related to a marked reduction in their fear of recurrence (section 8.3.2). This was further suggested by there appearing to be no significant differences between the heart attack patients' perspectives on lifestyle modification at approximately one year after a heart attack and the perspectives of CR patients who had not had a heart attack (section 8.2).

Importantly, these findings indicate that CR patients do not appear to view lifestyle risk reduction in terms of a series of targets, which may require lifestyle modification to achieve, as is advocated in current national standards and guidance (Department of Health 2000, Joint British Societies 2005, NICE 2007). Neither do CR patients appear to uncritically accept generalised advice about lifestyle changes that they are given on CR programmes. Rather, patients seem to relate information about lifestyle risk factor reduction to their own circumstances, which highlights the tension between approaches to CHD-risk reduction in the population at large and individual patients' perspectives (Davison 1991, 1992, Frankel *et al* 1991, Gambling 2003).

This tension has largely arisen from the application of population-based estimates of risk to individual people, in order to reduce the burden of CHD in the population (Davison *et al* 1991, 1992, Frankel *et al* 1991). In the UK, strategies adopted in government health policy include population-based risk reduction approaches and

approaches that target individuals deemed to be at high risk (Department of Health 1999, 2000). Population-based approaches aim to reduce the incidence of risk factors for CHD (especially those related to lifestyle) in the whole (low-risk) population in order to reach a small number of high-risk individuals (Department of Health 2000). Approaches that target individuals with a high baseline risk do so on the basis of epidemiological evidence that indicates that a disproportionately large number of CHD-related deaths (between thirty and forty percent) occur in the small proportion (less than twenty percent) of the population who are deemed to be at high risk (Jackson *et al* 2006, Manuel *et al* 2006, Rose 1985). Patients with established cardiovascular disease (e.g. those who have had a heart attack or CABG surgery) are considered to be at high risk, as assessed by algorithms such as the Joint British Societies' (2005) cardiovascular disease risk prediction charts, which are now in routine use in the UK. Subsequently, evidence-based national standards, such as the NSF for CHD (Department of Health 2000), and clinical guidelines (Joint British Societies 2005, NICE 2007) state that all of these patients should be prescribed appropriate medication (for example, to reduce their blood pressure and cholesterol) and be advised to meet a series of lifestyle targets, which for many patients requires lifestyle modification to achieve.

The difficulty with these approaches is that assessments of any individual person's risk, despite the sophistication of the technique (Joint British Societies 2005), remain based on population data. As such, they cannot predict with certainty which individual people will be affected by CHD, or which patients with CHD will experience further CHD-related events (Wheatley 2005). Indeed, a consequence of population-based approaches is the situation, which has been termed the "prevention paradox" (Rose 1985), where CHD-

related mortality substantially falls in the population but many people who reduce their lifestyle risk factors would not have had a heart attack anyway. An uncomfortable implication of this is that people may be unlikely to modify their lifestyles if they are told that statistically speaking they are unlikely to benefit on an individual basis (Davison *et al* 1991, 1992, Frankel *et al* 1991). To a lesser extent this also applies to approaches that target high-risk individuals, in that the approach itself may be effective in reducing CHD-related morbidity and mortality in the population but not all of the people who change their lifestyles would have been affected by CHD or experienced further CHD-related events had they not done so.

Nevertheless, in the pursuit of CHD-risk reduction in the population, considerable effort over the last several decades has been put into health promotion and health education strategies and activities, (such as CR programmes). In these a strong emphasis has been placed on heightening peoples' awareness of their risk of CHD and on their personal responsibility for reducing lifestyle risk factors (Davison 1991, 1992, Wheatley 2005). This makes the all-important step of personalising risk such that it moves from the population as a whole to the individual, which was described by Rose (1992) as a "rescue operation" but which Davison and colleagues (1991) described as "propaganda based on half-truth, simplification and distortion". Even so, discourses about risk in relation to public health in general have become an increasingly important feature of contemporary society that has transformed the way disease is defined and how health services are organised and delivered. The emphasis has increasingly moved from treatment to prevention, or from sickness to health (Armstrong 1995, Petersen & Lupton 1996). Subsequently, the impact that this has had on individuals has increased to the point where everyone is expected to take responsibility for care of themselves. This

involves taking a variety of preventative measures in relation to lifestyle and environmental risks, whilst at the same time minimising any potential for harm to others and the environment (Petersen & Lupton 1996). Government policy continues to emphasise personal responsibility, in which “choosing” a healthy lifestyle is promoted as a rational response to awareness of health risks (Department of Health 2000, 2003).

The ideology of risk-avoidance constituting rational behaviour and risk-taking constituting irrational behaviour remains a pervasive influence in health education strategies relating to CHD-risk reduction, especially those concerned with secondary prevention such as CR programmes (Wheatley 2005). This ideology has considerable resonance with traditional psychological models of risk perception and whilst various models have been proposed, a commonly used example in health promotion and health education is the Health Belief Model (Calnan & Rutter 1986, Lupton 1999). According to this model, people will take appropriate preventative action if they view themselves to be at significant risk of illness where there would be serious consequences and that taking preventative measures would be effective without the costs outweighing the benefits. In assuming a direct relationship between taking appropriate preventative measures and having adequate “knowledge” about the risk, this theory views failure to take preventative action as either due to patients’ ignorance or irrationality, for example, fatalistic “misconceptions” about CHD-related risk (Lupton 1999, Wheatley 2005, Whitehead & Russell 2004). This has often meant that health education strategies have been viewed in terms of dispelling ignorance and overcoming patients’ “misconceptions” such that they do “choose” to make rational decisions about lifestyle changes (i.e. that they follow lifestyle recommendations) and take more responsibility for their own health (Davison *et al* 1992, Wheatley 2005).

Subsequently, risk and health have become moral issues, in which failure to take action deemed necessary may be subject to self-blame and judgement by others (Petersen & Lupton 1996). There is much evidence of patients being blamed for causing their own illness as a consequence of the over-emphasis on lifestyle risk factors in causation (Lupton 2003, Annandale 1998, Traulsen & Bissell 2003). Risk factors such as hypercholesterolaemia and hypertension are increasingly being conceptualised as diseases in their own right (Heath 2005). As a result, hypercholesterolaemia (which may or not result from an “unhealthy” diet) has been associated with moral judgement (Lupton 1995). Studies have reported that where patients cited aspects of their lifestyle as likely causes of their heart attack, they often blamed themselves, felt guilty or thought that they had deserved it (e.g. Bergman and Bertero 2001, Fleury *et al* 1995, Jensen & Petersson 2003, Johnson & Morse 1990, Plach & Stevens 2001, Sutherland and Jensen 2000).

In this study, it did not seem that the patients thought that they were to blame for their heart attack, although only R5 explicitly talked about this and what he said suggested that he was trying to avoid blame (section 4.4.1), which supports the findings of other studies (French *et al* 2005, Treloar 1997). However, patients did tend to make justifications for aspects of their lifestyle that they had not changed (e.g. section 5.5.1) and for not changing aspects of their lifestyle enough, for example because of physical difficulties, as were discussed at the beginning of this section. This suggested that the moral pressure to follow lifestyle recommendations at least affected what some patients *said* about whether or not they had done so, even if it had not affected what they had actually *done* (Radley & Billig 1996).

This overtly rationalistic approach to risk has been criticised as being over-simplistic, especially that it fails to adequately allow for the dynamic influence that social and cultural factors have on people's perspectives (Lupton 1999, Williams 1995). This remains pertinent to this type of psychological model in general, even those that have attempted to account for social and cultural factors such as the Theory of Reasoned Action, the Theory of Planned Behaviour, and the Locus of Control concept, amongst others (a full review of these models is provided by Horne and Weinman (1998) since there is insufficient space in this thesis to discuss these models in depth). The findings of this study support these criticisms in demonstrating the sophistication of patients' perspectives on their risk and that their perspectives on bad luck or chance (i.e. fatalism) reflected their awareness that following lifestyle recommendations would not guarantee that they would not experience further CHD-related events (section 8.3.2). Indeed, in light of the prevention paradox and the inability of population-based assessments of risk to predict with certainty, this does not appear to be an irrational view.

Furthermore, patients were not ignorant or unable to understand the information they had been given about lifestyle risk reduction on the CR programme, as could be seen, for example, from their knowledge of what to "cut out" from their diets (sections 5.2.3 and 7.5). Instead they made decisions about the relevance of this information to their own circumstances, which did not necessarily involve following lifestyle recommendations. On this point, it has been well established that people's choice not to follow lifestyle recommendations (whether they have got CHD or not) is rarely because they are unaware that these aspects of lifestyle may constitute a health risk (e.g. Burrows & Nettleton 1995, Calnan & Williams 1991, Graham 1987, Lupton 1999, Pill &

Stott 1985, Williams 1995). Moreover, the emphasis on rationality and personal responsibility for reduction of lifestyle risk factors tends to overlook social and environmental causes of disease (Annandale 1998, Lupton 2003, Terris 1996, White 2002) and whilst well intentioned, has an element of authoritarianism. These issues are also pertinent to understanding patients' perspectives on taking medicines, which this discussion now moves on to consider.

8.4.2 Patients' perspectives on taking medicines

Before discussing the findings of this study in relation to the literature, it is important to consider the concept of "compliance" first, since this is a traditional way of viewing patients' approach to taking medicines. The significance of this is that by the mid-1990s a vast body of research indicated that many patients do not always take their medicines as directed, yet investigations into the causes of "non-compliance" have remained inconclusive (Donovan & Blake 1992, Vermeire *et al* 2001, Working Party 1997). Indeed, it has been argued that the concept of "compliance" is closely associated with issues concerned with control and the dominance of medicine (Donovan & Blake 1992, Heath 2003, Pollock 2005).

Lerner (1997) argues that "non-compliance" has been historically constructed, such that changing social and cultural factors have affected the language used to describe patients who do not follow doctors' orders. To illustrate this he shows how resentment towards immigrants to the US in the early 1900s led to tuberculosis patients who failed to follow medical advice being labelled as "irresponsible" and following the second World War labels such as "recalcitrant" were applied to tuberculosis patients who failed to take antibiotics. Lerner (1997) argues that this language reinforced the widely held

cultural belief that patients who failed to follow doctors' orders were deviant and deserved "aggressive remedial intervention". He particularly shows how the term "non-compliance", which was developed in the 1970s and intended to be a non-judgemental term, is still associated with these earlier notions of deviance. As a result "non-compliance" has more recently been recast as "non-adherence" in an attempt to emphasise patient choice rather than misbehaviour or deviance (Armstrong 2005). Nevertheless, compliance (and adherence) is still regularly defined in terms of the requirement for patients to "slavishly" follow doctors' orders (Lerner 1997).

There is a substantial body of research that demonstrates the sophistication and complexity of lay people's understanding of health and illness in relation to following doctors' orders (Bissell *et al* 2004, Donovan & Blake 1992, Pollock 2005, Williams & Calnan 1996). Donovan and Blake (1992), for example, in their study of rheumatology patients show how patients are quite capable of making informed choices about taking medicines without worrying about whether or not they are following doctors' orders exactly. Their findings demonstrate that "non-compliance" is not simply a matter of patients forgetting doctors' orders or being too ignorant to understand them (i.e. non-intentional non-compliance rather than intentional non-compliance) and that patients are generally not powerless or entirely passive.

Subsequently, the concept of compliance came in for increasing criticism and the traditional paternalistic model of the doctor-patient relationship, where doctors made decisions on behalf of their (passive) patients, increasingly came to be seen as outdated and no longer appropriate (Bissell *et al* 2004, Coulter 1999, Stevenson *et al* 2000, Working Party 1997). Repeated calls were made for the development of patient-

centred approaches, where discussion, negotiation and shared decision-making form key features of open, co-operative relationships between health professionals and patients. In response, a Working Party of the Royal Pharmaceutical Society was set up, which resulted in the concept of “concordance”.

In placing a “new respect for the patient’s agenda” at its centre, concordance then views the relationship between patients and health professionals in terms of promotion of discussion and dialogue (i.e. an negotiated exchange between equals), and not just an opportunity to reinforce or individualise instructions about treatment (Working Party 1997). However, concordance presents a considerable challenge to traditional medical authority and, despite considerable promotion over the last decade, there remains little evidence of widespread change towards this sort of interaction between health professionals and patients in practice (Armstrong 2005, Bissell *et al* 2004, Cox *et al* 2004, Jones 2003, Pollock 2005, Stevenson *et al* 2000). Indeed, the terms “concordance” and “compliance” are often used interchangeably, as if their meanings were essentially the same but the former is the currently acceptable way of expressing the latter, which has effectively subverted the originally intended meaning of concordance (Armstrong 2005, Bond 2003, Pollock 2005). Subsequently, this deeply entrenched authoritarian view of “compliance” continues to pervade professional and academic thinking. Whilst this is recognised, this view is not endorsed or supported in this discussion of patients’ perspectives on taking medicines.

In relation to CHD, numerous quantitative studies have found that a significant proportion of patients who have either had a heart attack or CHD requiring CABG surgery (i.e. who would have been eligible for CR, even if it was not stated that they had

attended a CR programme) do not continue to take their heart-related medicines (e.g. Arif *et al* 2007, Burke & Dunbar-Jacob 1995, Choudhry & Winkelmayr 2008, Ho *et al* 2006, Kopjar *et al* 2003, Lee *et al* 2007, Newby *et al* 2006, Rasmussen *et al* 2007, Shah *et al* 2007, Sud *et al* 2005, Ye *et al* 2007). The proportion of patients who take their medicines as prescribed varies between studies and between individual medicines. This may be partly explained by the variety of techniques used to measure compliance in these studies, such as tablet counts or patients' reported compliance (Lee *et al* 2007). A recent study, presented at the American Heart Association meeting in October 2007 (Shah *et al* 2007) found that patients' compliance with heart-related medicines after a heart attack significantly reduced over three years but that patients who attended a CR programme were more compliant with statin therapy at six months after discharge from hospital than those who did not. They found that at six months after discharge from hospital, ninety-one percent of patients still took a beta-blocker, eighty-five percent of patients still took an ACE inhibitor and ninety-four percent of patients still took a statin. However, at three years after discharge from hospital only forty-six percent of patients were still taking a beta-blocker, whilst only thirty-six percent of patients were still taking an ACE inhibitor and only forty-two percent of patients were still taking a statin. In contrast, a study of fifty-two CR patients between three months and two years after heart attack that found that all the patients reported that they took their medication, although data was missing for one patient. The authors seemed to have been surprised and doubted the authenticity of this finding on the basis that subjects may have reported desirable behaviour rather than actual behaviour, given the finding of non-compliance in so many previous studies (Leong *et al* 2004).

The findings of the few qualitative studies that have explored the perspectives of either heart attack patients or those with CHD requiring CABG surgery on taking heart-related medicines (as discussed in section 2.4.3) are equivocal; Wiles and Kinmonth (2001) reported that none of the heart attack patients in their study had considered stopping their medication, whilst Tolmie and colleagues (2006) found that some of the CABG patients in their study stopped taking their medicines for various reasons (e.g. side effects) but did not present the perspectives of patients who did take continue to take their medicines. Other studies reported a tendency towards taking medicines, but did not account for the views of heart attack patients who deviated from this tendency, by reporting that *most* of the patients seemed to be taking their medicines (Karner *et al* 2002) or used phrases such as that “good adherence” was *generally* found (Ononeze *et al* 2006).

In this study of CR patients, all of the patients consistently reported that they continued to take all of their heart-related medicines (sections 5.3.1, 6.5.1 and 7.6.1). This study provides detailed findings about CR patients’ perspectives on a wider range of medicines-related topics than any of the other studies that were found, such as the lengths that patients went to in order to make sure that they did take their medicines (e.g. the use of routines and physical aids), although some patients still forgot to take occasional doses (sections 5.3.1, 6.5.1 and 7.6.1). This study adds to the work of the only previous longitudinal qualitative study that was found that included findings about heart attack patients’ perspectives on medicines (Wiles & Kinmonth 2001). That study found that in the early few months after a heart attack patients continued to take their medicines, but the authors questioned whether patients would continue to do so over the longer term because of the findings of quantitative studies, such as those quoted in

this section above. Furthermore, their sample was drawn from a larger project, in which patients who had established CHD received a higher standard of care than patients might experience elsewhere (such as in this study, for example). This involved more contact with specific health professionals than was (and still is) usual following a heart attack, which raises the possibility (acknowledged by the authors) that some patients may not have continued taking their medicines had they not been visited at home by a nurse who, amongst other things, monitored their use of medication.

However, since the initial interview stage in this study occurred at a similar stage in patients' recovery as the second interview stage in Wiles and Kinmonth's (2001) study (i.e. shortly after patients had attended a CR programme), this study suggests that heart attack patients and indeed CR patients who had not had a heart attack do continue to take their medicines (by their own reports), at least up to a year after being discharged from hospital. Moreover, there was no indication that this situation was likely to change, on the basis of patients indicating that they had no intention of stopping their medicines (section 6.5.1) and that several of the patients had had their CABG surgery over two years prior being interviewed (section 3.3.3). This suggests that patients who attend a CR programme may be more likely to continue to take their medicines over a longer-term period than CHD patients in general, which may go some way towards explaining the apparent difference between studies in the proportion of patients who report continuing to take their medicines. It also supports Shah and colleagues' (2007) quantitative finding that more CR patients were still taking a statin at six months after discharge from hospital than patients who did not attend CR. Further longitudinal research that compares CR patients' perspectives on taking medicines over a number

of years with the perspectives of patients who do not attend CR programmes is warranted to address this issue.

Of greater significance than the finding that CR patients report continuing to take their medicines for a longer period of time than has previously been reported in the qualitative literature is the finding that patients were aware that the medicines had mainly been prescribed to reduce their risk of further CHD-related events (sections 5.3.3, 6.5.2 and 7.6.3). That patients chose to take the medicines to reduce their risk is consistent with them making assessments of their risk of experiencing further CHD-related events (section 8.3.2) and deciding whether this also meant that lifestyle changes were needed (section 8.4.1). This suggested that patients were not merely following doctors' orders. As such, this study shows how patients' perspectives on risk relate to both their perspectives on medicines and lifestyle modification in a way that has not been shown in other studies. Studies have reported that some patients viewed their heart-related medicines in terms of risk reduction (Attebring *et al* 2005, Ononeze *et al* 2006) or slowing the progression of CHD (Treloar 1997), as was discussed in section 2.4.3. In contrast, Karner and colleagues (2002) found that few patients viewed medicines in terms of risk reduction, whilst Bergman & Bertero (2001) reported that some patients viewed medicines in terms of aiding recovery. Other studies reported that either some or many patients did not know why their medicines had been prescribed (Roebuck *et al* 2001, Wiles & Kinmonth 2001). This study supports some of these studies by finding that patients mainly viewed medicines in terms of risk reduction but to a greater or lesser extent also perceived that they were aiding their recovery or controlling symptoms (sections 5.3.3 and 7.6.3).

When the views of heart attack patients and patients with CHD requiring CABG surgery are compared, the findings of this study suggest that the view of medicines aiding recovery may only apply to heart attack patients, only in the early recovery period afterwards and only to certain medicines (section 5.3.3), since in the second interviews patients only talked about their medicines in terms of risk reduction (section 6.5.2). Aspirin and statins were only talked about in terms of preventing further heart attacks, whereas beta-blockers and ACE inhibitors were talked about in terms of both risk reduction and aiding recovery. With the exception of R4 (section 6.5.1), the heart attack patients did not appear to be aware of medicines being prescribed for symptom control, even though some patients were taking medicines such as nitrates or nicorandil (section 5.3.3). In comparison, the patients who had CABG surgery did not talk about heart-related medicines aiding their recovery but two patients with a long history of angina prior to surgery did talk about their medicines controlling angina symptoms, although only R16 saw his current medicines in these terms (section 7.6.3).

Scrutiny of the patients' conceptions presented by the only study that was found that explored CHD patients' understandings of how individual heart-related medicines work (Karner *et al* 2002) similarly suggested that some patients viewed aspirin in terms of risk reduction but few patients viewed statins, beta-blockers and ACE inhibitors in these terms. The authors did not make this point however; instead they presented their findings in (rather patronising) terms of patients' lack of understanding and *misconceptions* about how their medicines work. In contrast this study found much greater variability in patients' understandings about how their medicines work; some patients were able to state which medicines reduced blood pressure, for example and which medicine reduced cholesterol, whereas other patients were not sure which

medicine did which and a few patients did not seem to know how any of their medicines work. On the other hand, many patients seemed to have difficulty remembering the names of all of their medicines (sections 5.3.3 and 7.6.3) and most patients did not talk about how their perceived causes of either their heart attack or CHD requiring CABG surgery related to how they thought that individual medicines could help prevent further CHD-related events. Those who did talk about this seemed to have found relating the two issues problematic (section 8.2). This suggested that patients may have taken explanations in the medicines-related information they were given at face value without necessarily considering how this related to their own circumstances.

The point here is not that patients *should* have known how individual medicines work or that they *should* have made the connection between the causes of their heart attack or CHD requiring surgery and how the medicines reduce risk, rather that there appeared to be a contrast between patients' approach to lifestyle modification and taking medicines. As was discussed in section 8.4.1, the aspects of their lifestyles that patients changed and maintained were generally those that were perceived as causes of their heart attack and they did not tend to maintain changes to aspects of their lifestyle that were not perceived as likely causes, even if it had been recommended that they should. However, all of the patients appeared to take all of their heart-related medicines (as best as they could), rather than deciding to take one medicine that related to a perceived cause but deciding not to take another because it did not relate to a perceived cause. It seemed that patients tended to view the rationale for exactly how each medicine reduced their risk of experiencing further CHD-related events, the subsequent specific choice of medicines and the doses as being technical matters,

which they trusted their doctors to know about. Indeed, some patients explicitly pointed this out, for example R7 (sections 5.3.2 and 6.5.2) and R13 (section 5.3.2).

This is not to say that just because patients appeared to place considerable trust in their doctor's knowledge that that they did not want to know how the medicines affected their bodies at all (e.g. whether they reduced blood pressure or cholesterol etc), since many patients did, or that they accepted medicines uncritically. Many patients expressed a sense of disquiet about taking medicines, especially concerning the potential for medicines to cause harm, and tended to take a particular interest in medicines information that related to these issues (sections 5.3.2, 6.5.1 and 7.6.2). This has been reported by a number of studies of heart attack patients or CABG patients (Attebring *et al* 2005, Bergman & Bertero 2001, Johansson *et al* 2003, Karner *et al* 2002, Roebuck *et al* 2001, Tolmie *et al* 2006), as well as being widely reported in the literature more generally (Pollock 2005, Pound *et al* 2005). In this study, patients tended to consult their doctors about their concerns (sections 5.3.2, 6.5.1 and 7.6.2) and either tolerated or sought medical advice about side effects, rather than just discontinuing the medicines thought to be responsible (section 8.2), or engaging in any covert activities. This is in contrast to other studies of CHD patients that found that patients stopped taking medicines because of side effects (e.g. Tolmie *et al* 2006) or stopped medicines in a trial and error process to find out which one was causing a specific side effect (e.g. Crane 2001). As such, it was felt that the term "disquiet" better represented the perspectives of the patients in this study than the more strongly termed "medicines resistance" (Pound *et al* 2005).

In short, it appeared that CR patients continued to take their heart-related medicines (by their own reports) because they saw them as being important to reduce their risk of experiencing further CHD-related events, which followed from their assessments of their risk and their choices about what was necessary to reduce their risk. This was not a matter of merely following doctors' orders, although patients appeared to trust their doctors to know technical details about the use of medicines, such as exactly how they reduced risk. However, this did not mean that patients did not want to know how the medicines affected their bodies at all, nor did they accept the medicines uncritically. Rather, they tended to actively seek information and medical advice about their concerns, especially in relation to side effects. These findings have implications for the future practice of health professionals and the improvement of CR programmes, which the discussion now moves on to consider.

8.5 Implications for professional practice

The findings of this study suggest that CR programmes could be improved by providing individualised information to patients, especially about lifestyle. This means providing information that is relevant to each patient, in sufficient detail to meet their individual needs and in a format that each of them is comfortable with. This echoes the implications of other studies of CHD patients' perspectives (e.g. Gambling 2003, Wiles & Kinmonth 2001) and the findings of a review of written information about medicines given to patients more generally (Raynor *et al* 2007). Where verbal information is provided in a group format (such as in the CR programme in this study), not all of the information may be relevant to all of the patients, for example giving dietary advice to patients who have read the written information given before discharge from hospital and do not think their diet needs changing (section 7.5). Some patients may want more

information than others about certain topics and some patients may feel uncomfortable asking questions in front of a group. This suggests that at least some, if not all, of the information would be better provided on a one-to-one basis, rather than to a group.

Health professionals need to recognise the sophistication of patients' assessments of their risk of experiencing further CHD-related events and the choices they make to reduce this risk. This means moving away from the view that patients should be "compliant" with lifestyle targets or medicines and the moral implications associated with this view (section 8.4.1). In relation to information about medicines, patients should be given more information about the potential for medicines to cause harm, which health professionals continue to have reservations about (Raynor *et al* 2007), despite being included as a standard in the NSF for CHD (Department of Health 2000). In addition, discussing patients' concerns about medicines more generally needs to be afforded greater priority by health professionals, rather than waiting until patients decide to raise their concerns; this may mean that patients decide not to take, or continue taking a particular medicine but may equally lead to a more patient-centred approach, even concordance. Having discussed the significance of the findings, how these relate to the literature and the implications of the findings for professional practice, the discussion now turns to consider the practical application of reflexivity in the study.

8.6 Reflexivity: practical application in the study

Theoretical considerations about reflexivity have been discussed in section 3.2.4, where it was pointed out that the process of reflexivity involves assessing the effect of the researcher on the research process (Hall & Callery 2001), which is linked to the quality of a qualitative study (Seale 1999). To this end, whilst I have attempted to present the

patients' perspectives as honestly as I can, at the same time I recognise that this thesis is the product of the interaction between the patients and myself and is socially contingent. That is to say it is constructed by the patients and myself and is affected by a variety of factors, rather than representing some sort of objective reality (section 3.2.2). There were numerous occasions in the interviews where patients referred to a technical procedure (such as angiography), an event or a medicine (amongst other examples) in their own way and in such terms that may have been problematic for a researcher without detailed knowledge of cardiology, pharmacy practice or the way that hospitals operate. This did not hinder the flow of conversation because patients expected me to know what they meant but this did introduce shared understandings or shared meanings into the construction of the data because I did know what they meant. Subsequently, some degree of translation or interpretation of that shared understanding has been necessary in order to justifiably articulate the patient's perspective, but at the same time this means that my account of that shared understanding remains to a greater or lesser extent my interpretation of what patients meant, rather than necessarily what they actually meant. In addition, acknowledging in the interview that I did understand what patients meant potentially put me in the situation of being seen as a representative of an authority or an institution, which affected what they said, especially about morally sensitive topics.

Richards and Emslie (2000) have highlighted how the professional role of the interviewer might impact on qualitative interviews. They observed that the higher social status of the "doctor" tended to overshadow personal characteristics, such that deference from working-class interviewees was frequently encountered, which was not found with middle-class interviewees. In contrast, there was a tendency for the

professional identity of the sociologist to be overshadowed by personal characteristics, such as age and gender, which identified her as “the girl from the University”. They also observed certain differences in interview content, for example that interviewees would ask the “doctor” health-related questions whereas interviewees would tend to talk about topics that were not health-related with the sociologist. In this study, despite efforts to present myself as a researcher and not as a pharmacist, it became clear in the interviews with heart attack patients that they were aware of me being a pharmacist and it seemed that this was why they especially expected me to know about medical procedures and medicines, for example. Subsequently, I felt that my professional identity as a pharmacist did seem to overshadow my personal characteristics and led to a tendency to be asked health-related questions. Similarly, I felt that patients talked in more detail about issues concerned with taking medicines (e.g. side effects) than they might otherwise have done. The CABG patients were not recruited from the CR programme (section 3.3.3) and it was easier to avoid being seen as a pharmacist or a health professional. Subsequently, I found that there was less expectation placed on me to understand medical matters and two patients (R19 and R28) asked me if I intended to become a heart surgeon when I had finished doing the research, which was similar to the questions that Emslie reported being asked (Richards & Emslie 2000).

Other factors that had an influence on the construction of the data included the patient recruitment procedure, the location of interviews and the presence of partners in the interviews. As discussed in section 3.3.3, the heart attack patients who volunteered to participate did so after I had made a brief presentation to the whole group at the CR programme and on a face-to-face basis. To a certain extent, patients’ decisions to volunteer would have been influenced by their perceptions about me and probably more

so than by the Patient Information Leaflet about the study (sections 3.3.2 and 3.3.3), although I got the impression that for some patients volunteering was a way of expressing their gratitude for the care they had received (section 4.4.3). As a result, the construction of the data as a whole was influenced by the way that I presented the study to the patients. This similarly applied to the recruitment of patients with CHD requiring CABG surgery because I wrote to them to invite them to participate, although they did not meet me in person prior to the interview.

The interview location was entirely the patients' choice and whilst most chose to be interviewed at home, some of the heart attack patients chose to be interviewed at the hospital to coincide with outpatient appointments (section 3.3.4). Efforts were made to provide an environment that was as informal as possible under the circumstances (as discussed in section 3.3.4), but I recognise that the location was more likely to make me appear to be an official figure, or a representative of the hospital, than if the interview had been conducted in the patient's home. The effect of this may have been that patients were more likely to either avoid disclosing any information that could have made them appear morally reprehensible or present this information in such a way that did not detract from their worthiness (Radley & Billig 1996). An example of this was lifestyle modification, since there is a certain moral pressure to follow lifestyle recommendations, as was discussed in section 8.4.1.

The effect on the data of a partner being in the interview was more complex. Partners were included either because the patient wanted their partner to be present (section 3.3.4), or that it was difficult to exclude the partner when they arrived with the patient for the interview or were present when I arrived at their home. In some interviews the

patient called to their partner who was in another room to help them remember sequences of events, for example. This influenced the construction of the data in a number of ways. Some patients seemed to volunteer more information than they might otherwise have done (e.g. R1 as discussed in section 3.3.4), whilst in the initial interview with R3 there appeared to be a certain tension between her and her husband about the amount (or rather, lack) of exercise that she was doing. Although both the patient and her husband talked to me, rather than directly to each other, there appeared to be a dialogue going on between them that resulted in her making numerous justifications about the exercise she was doing and why she could not attend an exercise class (section 5.2.2). In other interviews the patient and their partner would tell a particular story together, especially the experience of having a heart attack, whereas in other interviews the partner expressed their feelings of fear or anxiety, for example, and the patient seemed to play down their own concerns (R7 and R26 seemed to be examples of this).

Since the focus of the study was on the patient's perspective, themes that directly related to partners' perspectives have not been reported and contributions from partners have been considered in the context of how this appeared to affect what the patient said. This was not an entirely clear-cut process and I accept that in these situations the data remains, to a greater or lesser extent, a construction between the patient, their partner and myself, although I have attempted to present the patient's perspective above the partner's as much as possible. Whilst the partners' contributions offered insights into the patients' perspectives and the wider impact of the patients' illness on the family, to my mind they did not significantly affect the main findings of the study on patients' perspectives on risk, lifestyle modification and medicines.

Conclusions

This study explored CR patients' perspectives on medicines and lifestyle modification in relation to their perspectives on CHD (particularly on the risk of experiencing further CHD-related events), which remains under-reported in the literature. Whilst findings are presented about the experience of either having a heart attack or CHD requiring CABG surgery and the impact that this had on patients, the key findings of this study are as follows:

CR patients seemed to make sophisticated yet uncertain assessments of their risk of experiencing further CHD-related events, in which various factors were considered. This did not just involve identifying a likely lifestyle cause or causes of their CHD that might, if not modified, lead to another CHD-related event, or attributing the likelihood to chance or heredity alone. Their assessments tended to also include consideration of information about the damage done to their heart or how their heart was functioning. In doing so, patients related general information about CHD-risk factor reduction to their own circumstances. This incorporated information about their heart function in order to individualise their assessments of their risk of experiencing further CHD-related events, in the face of much uncertainty. Fear of recurrence appeared to be commonly experienced by heart attack patients and appeared to heighten their perception of being at risk, but this seemed to be a short-term effect and in the longer-term their perspectives on risk appeared to be similar to CR patients who had not had a heart attack.

Rather than seeing lifestyle recommendations as a set of standards that their lifestyle should match to reduce the risk of experiencing further CHD-related events, CR

patients tended to only make and maintain changes to aspects of their lifestyle that were perceived as likely causes of either their heart attack or CHD requiring CABG surgery. This appeared to be consistent with their perspectives on their future risk. Some heart attack patients initially made changes to aspects of their lifestyle that they had not cited as causes of their heart attack, which seemed to be associated with their heightened perception of risk and over time these changes tended not to be maintained.

CR patients continued to take their heart-related medicines (by their own reports) because they saw them as being important to reduce their risk of experiencing further CHD-related events, which followed from their assessments of their risk and their choices about what was necessary to reduce their risk. This was not a matter of merely following doctors' orders, although patients appeared to trust their doctors to know technical details about the use of medicines, such as exactly how they reduced risk. However, this did not mean that patients did not want to know how the medicines affected their bodies at all, nor did they accept the medicines uncritically. Rather, they tended to actively seek information and medical advice about their concerns, especially in relation to the potential for medicines to cause harm or because they were experiencing side effects.

These findings add to the literature by suggesting that CR patients' assessments of their risk of experiencing further CHD-related events may be more sophisticated than previously reported and an integral part of CR patients' choice to continue taking their heart-related medicines, as well as their choices about lifestyle changes. In particular, the findings suggest that CR patients continue to take their heart-related medicines (by

their own report), in contrast to the findings of quantitative studies and for a longer duration of time than has previously been found in qualitative studies. The implications of these findings include the need for health professionals to recognise the sophistication of CR patients' CHD-risk assessments and to move away from the view that patients should be "compliant" with lifestyle targets or medicines and the moral implications associated with this view. It seems that CR patients require individualised information about lifestyle and medicines, especially about the potential for medicines to cause harm, and discussing patients' concerns about medicines more generally needs to be afforded greater priority by health professionals.

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Appendix 1: Patient and Carers Information Sheet

Study Title

A qualitative study of Cardiac Rehabilitation patients' perspectives on Coronary Heart Disease and treatment.

Invitation Paragraph

You are being invited to take part in a research study. You do not have to take part but before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me (Simon White, [telephone number]) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The aim of the study is to find out about Cardiac Rehabilitation patients' experiences of having a heart attack or heart bypass surgery. I also want to find out what patients feel about their treatment and what information they've been given about their treatment.

Why have I been chosen?

You have been chosen because according to Cardiac Rehabilitation records kept at [Hospital] you have previously had a heart attack or heart bypass surgery. A selection of patients who have had a heart attack or heart bypass surgery have been invited to take part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this form to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part and what do I have to do?

If you decide to take part you will be invited to have a discussion with me to tell me about your experiences, which I would like to audiotape. I will arrange for the discussion to take place at a time and place that is convenient for you. The discussion will probably last about an hour and will be about your experiences of having a heart attack or heart bypass surgery, your treatment and information you have been told or given to do with your treatment.

What are the possible risks and disadvantages of taking part?

Taking part will not affect your treatment or disease state in any way. I will show you appropriate identification before the discussion so you can be sure that I am genuine. I am not aware of any disadvantages to you in taking part in this study.

What are the possible benefits of taking part?

There are no specific advantages to you in taking part, although what you tell me may benefit you and other patients in the future by helping to improve the service offered to patients.

What if something goes wrong?

You can contact me if you wish to complain, or have any concerns about any aspect about any way you have been approached or treated during the course of this study. I will consider such reports promptly and take appropriate action immediately. Alternatively the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it

What will happen to the research records?

The audiotape of the interview will be kept secure and confidential in a locked cupboard. At the end of the study the audiotape will be destroyed.

What will happen to the results of the research study?

The results of the research will be published as a full report, as research papers in academic and professional journals and presented at conferences. If you would like a copy of the results, please let me know either in writing or by telephoning (see contact details at the bottom of this sheet). No individual patient will be identifiable in any of the reports, papers or results.

Who is organising the research?

The study is being organised by the Centre for Pharmacy, Health and Society at the University of Nottingham and myself for a higher research degree. [Hospital] NHS Trust supports the study.

Who has reviewed the study?

The design of the study has been reviewed by my supervisors (Professor Claire Anderson and Dr Paul Bissell) at the University of Nottingham and by representatives from [Hospital] NHS Trust. The study has been approved by the Local Research Ethics Committee.

Contact for further information

If you have any questions or require any further information, either now or at any time during the study, please contact me (Simon White) c/o Pharmacy Department, [Hospital], [Address]. [Telephone number] or [My University eMail address].

Thank you for taking the time to read this information sheet

(The original form was on hospital headed paper)

Appendix 2: Research Consent Form

Study Name: A qualitative study of Cardiac Rehabilitation patients' perspectives on Coronary Heart Disease and treatment.

Investigators Name: Simon White, c/o Pharmacy Department, [Hospital] NHS Trust.

Please tick

1. I agree to take part in this study. ☐
2. I have had time to read the Patient Information Sheet and I understand it. ☐
3. The study has been fully explained to me, and my questions have been answered. ☐
4. I understand what I am expected to do. ☐
5. I am free to stop being in this study at any time. If I want to stop, I do not have to give any reason. ☐
6. If I choose not to take part in this study or to stop, I know that my care or legal rights will not be affected in any way. ☐

Patient

Name:.....

Signed:.....

Contact telephone Number:.....

Dated:.....

Researcher

Signed:.....

Dated:.....

(The original form was on hospital headed paper)

Appendix 3: Initial Stage interview Guide

Get basic demographic information: age, gender, ethnicity and occupation.

1. Perspectives on CHD

Could you tell me what happened to you to cause you to be in hospital and now on the CR programme? (Stories about illness)

What impact has your heart problem had on your life? (Lifestyle changes made, concerns and anxieties, how it feels to have CHD etc)

What have you been told about your illness and by whom?

2. Perspectives on medicines

Were you taking any medicines before you went into hospital?

After your heart problem started were any new medicines started or were any of your existing medicines altered at all?

What effect has taking these medicines had on your life? Do you take the medicines that you have been prescribed? If not, prompt for reasons why

Can you tell me how you think the medicines work? (Explanatory models of how the treatment works)

3. Sources of medicines information and education

How have you found out what you know about your medicines? (Sources used)

If necessary prompt: Have you been told about any of your medicines?

If so, can you tell me what you were told and who it was who told you?

Have you been given any written information about any of your medicines?

If so, can you tell me what information you were given?

Who gave you the information?

Did you find this helpful, or not?

How do you feel about this information you have been given about your medicines? (Satisfaction)

4. Experiences of pharmacists

Have you spoken to a pharmacist (chemist) about your medicines since your heart trouble started?

If so, can you tell me what was discussed and when?

Did you find this discussion helpful?

Did you feel that there was anything else the pharmacist could have done for you?

If not, would you have liked to discuss your medicines with a pharmacist?

If so, what would you would have wanted to talk about?

Is there anything else you want to add? Thank you.

Appendix 4: Second Stage Interview Guide

Remind patient of some of the things talked about in the first interview.

1. Ongoing experiences of CHD

How have things been for you with your health since we last spoke? (Ongoing experiences of CHD): what has changed since we last spoke and why?

Use this section to help the patient relax and get them talking

2. Contact with health professionals and ongoing access of health services or patient groups

Do you still see your GP or practice nurse regularly?

Are you still in contact with the hospital or community CR Nurses?

Have you talked to a pharmacist (chemist) about your medicines etc since we last spoke?

Are you involved with any self-help groups or other groups for people who have had a heart attack or heart problems more generally? (Explore for reasons)

3. Perspectives on the risk of having another heart attack

What do you think caused you to have your heart attack?

Do you worry that you might have another heart attack? What impact has this had on your life since you had your heart attack? (I.e. their view of risk)

4. Perspectives on treatment

Do you still do regular exercise? (and if relevant, do you go to the gym regularly?)

Do you still maintain the dietary changes made? (and other lifestyle modification measures – explore for reasons)

How are you getting on with your medicines these days? (prompt for side effects or problems with medicines)

Do you (still) take these medicines everyday?

If not, ask about reasons why

Note: May need to say before asking the questions about medicines and lifestyle modification that I am not judging the patient or checking up on them and that this is strictly confidential; I just want to know what they actually think and whether they actually take the medicines and have maintained lifestyle changes.

Wind interview down with: is there anything else you want to add? Thank you.

Appendix 5: Third Stage Patient Letter

Dear [patient name],

I am currently conducting research into Cardiac Rehabilitation patients' perspectives on Coronary Heart Disease and treatment as part of my PhD thesis at the University of Nottingham. An important part of this research involves talking to people who have had heart bypass surgery about their experiences of their illness and aspects of their treatment, such as coping with lifestyle changes and taking medicines.

I would like to ask you to take part in this research. Your own views about having heart bypass surgery and its treatment are extremely important and will contribute to an increased understanding of Coronary Heart Disease. All that is involved is a conversation with myself at a location convenient to you. Further information is contained in the Patient Information Sheet, which is enclosed with this letter. If you do agree to take part I would be grateful if you would complete the enclosed Research Consent Form and return it to me in the stamped, addressed envelope enclosed with this letter. There are no other forms or questionnaires to complete. I will then contact you by telephone to arrange a convenient time and place to meet. Anything you say to me will be treated with the strictest confidence.

You are under no obligation to take part and the care that you receive from your doctor or from any other health service professional will not be affected in any way if you choose not to take part.

Thank you for your help.

Yours faithfully,

Simon White

Encs

(The original form was on hospital headed paper)

Appendix 6: Third Stage Interview Guide

Get basic demographic information: age, gender, ethnicity and occupation (? unless retired).

1. Perspectives on CHD

Could you tell me what happened to you to cause you to be in hospital and to then have Cardiac Rehabilitation? (Stories about illness: use this section to put the patient at ease)

What impact has your illness had on your life? (Probe the impact on family life, occupation, financial situation etc – ask for examples of how things changed)

How have you coped with your illness?

What impact has having heart bypass surgery had on your life? (E.g. do you still get symptoms? Did you have any complications or problems because of the operation?)

What have you been told about your illness and by whom?

Do you have any concerns and anxieties about the future? (How it feels to have CHD etc)

What did you think of the Cardiac Rehabilitation programme? (Explore the impact that cardiac rehabilitation had on the patients' life)

2. Perspectives on risk of further CHD-related events

What do you think caused you to have heart problems? (Explore ideas of preventability versus inevitability – i.e. their view of risk)

Do you think that you might have more heart problems? (If yes, explore how the patient subsequently feels about this, e.g. makes them feel anxious. Also probe their view of future risk by asking how risk has been explained to the patient and how they understand or make sense of it – e.g. is the patient's view of risk different to what they have been told)

3. Perspectives on treatment

Note: Comment before asking questions about treatment that I am not judging the patient or checking up on them and that this is strictly confidential; I just want to know what they actually think about lifestyle modification and the medicines and whether they actually take them.

What do you think about the recommendations for doing exercises?

Do you do the exercises (and if relevant, do you go to the gym regularly)?

Do you do more or less than you did previously (e.g. compared to the time of the CR programme)? Ask why and look for examples.

What do you think about the recommendations for changing your diet/ eating healthily?

Do you follow the dietary advice given (and other areas of lifestyle modification)?

Do you follow the advice more or less than previously (e.g. compared to the time of the CR programme)? Ask why and look for examples.

Explore whether their perspectives on lifestyle modification have changed over time.

Were you taking any medicines before your heart problems started/ you went into hospital?

Were your medicines altered after you had your bypass operation? Have your medicines been altered since? (I.e. explore patients' recollection of their drug history)

How do you cope with your medicines regimen? Prompt: Do you always take the medicines that you have been prescribed? (Check for missed doses).

If not, ask why, and which medicines don't get taken and when.

Explore whether their perspectives on taking medicines have changed over time.

What effect has taking these medicines had on your life? What is it like having to take these medicines? (E.g. experiences of side effects)

Explore issues of why the patient does take their medicines

Can you tell me why you think the medicines were prescribed? (Explanatory models of how the treatment works: e.g. risk reduction, symptom control or specific mechanisms of action)

4. Sources of medicines information and education

How have you found out what you know about your medicines? (Explore sources of information)

Have you asked for information about your medicines?

If necessary prompt: Have you been told about any of your medicines?

If so, can you tell me what you were told and who it was who told you?

Have you been given any written information about any of your medicines?

If so, can you tell me what information you were given?

Who gave you the information?

Did you find this helpful, or not?

What do you think about the information you have been given about your medicines? (I.e. how useful was it)

5. Contact with health professionals and ongoing access of health services or patient groups

Do you see your GP or practice nurse regularly? (Explore what happens when the patient does see their GP or practice nurse)

Has this changed at all since your heart problems started? (Explore how and look for examples of how things have changed.)

Do you talk about changes to your lifestyle with your doctor? (Explore for examples)

Do you talk about your medicines with your doctor? (Explore for examples)

Do you ask your doctor questions about your medicines? (Explore for examples)

Have you had any problems with your medicines that you have talked about with your doctor? (Ask for examples if relevant)

Have you had any problems with your medicines that you have not talked about with your doctor? If so, explore why.

Are you still in contact with the hospital or community Cardiac Rehabilitation Nurse? (If so, explore what sort of contact the patient has and what support is offered)

Are you involved with any self-help groups or other groups for people who have had heart problems? (Explore for reasons why if they have or if they have not)

Gradually wind interview down and finish with: Is there anything else you want to add?

Thank you.