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THEY DID EXPLAIN EVERYTHING, BUT I CAN'T REMEMBER: THE SEARCH FOR RELEVANT INFORMATION FOLLOWING A HEART ATTACK

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ABSTRACT

This qualitative descriptive study was undertaken to find out what information patients and their partners wanted following a heart attack. There were 17 participants, of whom 11 were patients and six were partners. Semi-structured interviews were conducted with participants and then thematic content analysis was used to identify the four main themes. The first two themes relate to the experience of having a heart attack and question the widely held belief that it is a dramatic experience and that patients deny what is happening. It seems more likely that the non-specific and insidious onset leaves patients genuinely not knowing what is happening. Women have an additional problem in that once they seek professional help, the medical staff often fail to correctly diagnose that they are having a heart attack.

The third and fourth themes relate to the recovery period and show that in spite of a plethora of information provided during cardiac rehabilitation, there is strong evidence that patients and partners fail to receive information that meets their own needs in relation to social, physical and psychological issues. This has an impact on the major adjustments to be made after a heart attack and the coping strategies that are a part of this. An additional problem following discharge is poor communication between health professionals, resulting in anxiety for patient and partners.

The role of the cardiac educator emerged as extremely useful and valuable to patients and partners as a support and source of relevant information after discharge. Further support and training for these nurses and expansion of the service would increase their availability to patients and partners. It would also be in line with the World Health Organisation (WHO) (1997) recommendations to provide an environment, which supports and motivates people to make lifestyle changes. An additional recommendation is increased flexibility in cardiac rehabilitation with a shift into the primary care setting, thus offering wider opportunities for patients and partners to obtain support and hopefully facilitate the process of adjustment following a heart attack.

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INTRODUCTION

INTRODUCTION TO CHAPTER

During the last three decades, there has been a decrease in the incidence of ischaemic heart disease (IHD) of 50% in New Zealand, yet the mortality rate is approximately 12,000 a year with 10,000 patients being discharged from Hospital (Ministry of Health (MOH), 1997). IHD includes patients suffering from coronary heart disease in which by far the largest problem is myocardial infarction (MI), otherwise known as a heart attack.

Apart from the impact on people themselves, these figures have major cost implications for the health services in terms of both primary and secondary care. Two main factors are believed to contribute to the continuing high rates of mortality and morbidity, one is the failure to receive correct treatment early enough (Pearson, 1999b), and the other is presence of risk factors, many of which it is believed can be reduced by people making lifestyle changes (MOH, 2000).

Early treatment for an MI is with drugs which aim to reduce the amount of permanent damage to the heart, by reducing patient's stress and breaking down the clot(s) which are preventing the blood supply reaching the heart muscle (Pearson, 1999b). Once patients have been admitted to hospital in New Zealand, they start on a three-phase education programme as part of a cardiac rehabilitation programme recommended by the National Heart Foundation of New Zealand (NHF). A main focus in this education programme is to reduce risk factors by encouraging lifestyle changes.

This study used semi-structured interviews to find out what information patients and partners want following a heart attack. Interviews took place in two different areas, once patients had been discharged from hospital. As all the patients had been started on a cardiac rehabilitation programme, much of the data relates to the education they received within this programme. Other data obtained covers the experience for patients and partners of and after the heart attack.

AIM OF THE STUDY

The original aim of this study was to answer two questions, question one was "what information do patients and partners want following a heart attack?" Question two was "what factors influence whether lifestyle changes are made?" These questions were shaped in conjunction with a local branch of the National Heart Foundation of New Zealand who wanted to know whether it would be useful to make a video specific to the needs New Zealand patients and their partners. It soon became obvious that these questions would be better addressed in two separate research studies, and question one became the main focus of the study.

The chosen research design was qualitative which produced considerable data on the first question and linked into adjustments that follow a heart attack. The second question was almost immediately identified as a problem, particularly as several patients had already made lifestyle changes before the heart attack. To address this question properly it would be preferable to reword it to see why people do not make changes, and would ideally involve patients over a longer time scale and some time after their heart attack. Participant entry criteria for the study as discussed in Chapter 3, might also need narrowing down. As a result this study only examined the question: What information do patients and their partners want following a heart attack? Having this question as the main study aim also meant that participants were referred to as patients or partners throughout the research, even when they had returned home.

ISCHAEMIC HEART DISEASE AS A HEALTH PROBLEM

IHD is the highest global cause of mortality causing 7.2 million deaths annually (WHO, 1997a). The diagnostic category IHD is used to denote coronary heart disease that does not include other diseases of the circulatory system such as stroke (Hay, 1996). Since the late 1960s, IHD deaths in New Zealand have fallen by over 50% (WHO, 1997a), but still remain the leading cause of death (MOH, 2000). One of the biggest shifts in the twentieth century has been the change "from acute or infectious diseases to chronic or multifactorial disorders as the major cause of mortality and morbidity" (Davison, Franhel & Smith, 1997, p.24).

Disability and social and economic consequences also result for people who suffer and survive with IHD. Costs given for patients living with circulatory diseases, which include stroke as well as IHD, are 10% of direct health care costs in developed countries (WHO, 1997a). New Zealand figures for 1990/1991 of costings for hospital admissions for chest pain, myocardial infarction (MI) and related surgical procedures, were estimated at $179 million for that one year (MOH, 1997). Cardiovascular disease, which combines IHD and strokes, accounted for 11% of public hospital discharges in 1997 (MOH, 2000). A major contributory cause of IHD is reported to be the presence of risk factors.

RISK FACTORS

Moffat and Harper (1997, p.11) define risk factors as, "Factors which predispose an individual to a higher risk of developing a disease, and also to factors implicated in the progression, severity and outcome of the disease process." The term risk factor was first used for cardiac diseases (Ewles & Simnett, 1999). The MOH (2000) now state, "the risk factors of today are the diseases of tomorrow" (p.6). "Primary avoidable mortality" (MOH, p. 314) is the phrase used to define conditions that it is believed can be prevented by reducing risk factors, either through individual lifestyle modification, or public health policy.

In New Zealand, the MOH (2000) state that lack of exercise is becoming a public health issue that is second only to smoking. Lack of physical activity increases the risk of obesity, a risk factor in itself. This assumption is based on

1996 figures that attribute 2143 deaths to lack of physical inactivity, 1073 to obesity and 4302 to smoking (MOH, 2000). If morbidity figures are included the impact is even greater. Whilst these figures do not only relate to deaths from IHD, all the risk factors are ones recognised as contributing to IHD, and they do this by causing arterial changes.

Arterial changes which can lead to an MI

The coronary arteries are the arteries that supply blood to the heart. Partial or total occlusion of the coronary arteries will impact on the heart's ability to provide the rest of the body with its necessary oxygen and nutrients that are transported by the blood. If more than 75% of a coronary artery is obstructed, the obstruction is considered to be significant or severe (Pearson, 1999a). The most common form of occlusion is from atherosclerosis.

Atherosclerosis

This is the term given to narrowing or partial blockage of arteries and usually occurs over several years. There is now a widely held belief that damage starts in youth and is compounded in societies where the diet contains high levels of saturated animal fat (Carter & Mason, 1998), which result in high cholesterol levels in the blood.

Cholesterol forms into fatty plaques, which adhere to the arterial walls narrowing the arteries and causing damage to the arterial linings. Smoking, hypertension and diabetes all play a role in aggravating the effects from the narrowing or the damage to the lining (Beaglehole & Bonita, 1994; WHO, 1997a). The result of this damage to the arteries is reduced elasticity, requiring the heart to pump harder to get the blood round the body. This in turn increases the blood pressure and causes more damage. The damage to the walls also makes it easier for the fatty plaques to adhere to the arterial linings (Carter & Mason, 1998), and this can lead to angina or an MI. A brief overview of the two conditions of angina and MI are given below.

Angina pectoris

Heart muscle can stay alive with as little as 10-15% of its blood supply getting through (Tortora & Anagnostakos, 1987), but the reduced oxygen supply will weaken the cells resulting in ischaemia. It is the reduced oxygen to the muscle tissue and consequent need for the heart to work harder that results in pain.

There are two classifications for angina, the first being stable angina. This is described as predictable, which means it has not changed in nature in the previous two months. It can be controlled by anti-anginal medication (Pearson, 1999a). The most common of these are coronary vasodilators, which are given by oral spray, sublingually or by controlled release from skin patches. Glyceryl Trinitrate (GTN) is a commonly prescribed coronary vasodilator. As stable angina occurs following increased demand on the heart, patients are often advised to take GTN as a preventative measure before they physically exert themselves. Additional advice given to patients if the pain is unrelieved is to repeat the tablets or spray every 5 minutes up to 20 minutes. If pain persists after this, then medical help should be sought urgently. The other type of angina is unstable angina that occurs at rest. This is unpredictable and usually fails to respond to anti-anginal medications. If untreated, "unstable angina carries a high risk of morbidity and mortality" (Pearson, 1999a, p.45).

Symptoms of angina can include chest pain, constriction or tightness in the chest, laboured breathing, weakness, dizziness and sometimes "a sense of foreboding" (Tortora & Anagnostakos 1987, p.468). These are similar to symptoms of an MI, which can result in confusion in the initial medical diagnosis.

Myocardial Infarction

This is the medical term for a heart attack and this happens when "the myocardium is deprived of oxygenated blood as a result of an occluded or partially occluded coronary artery/arteries" (Pearson, 1999b, p.42). The most common cause is a blood clot becoming trapped where fatty plaques have caused narrowing of the arteries and this causes pain. During a heart attack, pain can be in the centre of the chest and/or is commonly held to radiate down the left arm although in reality pain may be experienced in many different sites and in many different ways (Zerwic, 1998). Nausea, pallor, sweating and fatigue may also occur, as may breathlessness.

The location of the blockage affects the size and amount of heart damage where the heart muscle has been deprived of oxygen. Muscle necrosis begins 20-30 minutes after the first pain. Eventually, the dead tissue is replaced by scar tissue, and this normally occurs from one to twelve weeks after the attack. Failure to self-diagnose a heart attack has the potential to delay seeking help, yet time is a crucial factor in the treatment process (Meischke, 1999).

TREATMENT OF AN MI

Once a person has presented to a doctor, the diagnosis of an MI depends on correct interpretation of the symptoms and then an electrocardiograph (ECG) and taking bloods for cardiac enzymes. During a heart attack, certain enzymes are released into the bloodstream and provide specific markers that a heart attack has occurred (Pearson, 1999b). Treatment in the acute stage aims primarily at reducing the amount of damage to the heart. This includes coronary vasodilators, thromboembolytic drugs to dissolve the blood clot, and morphine to relieve pain and reduce anxiety. All of these are given intravenously and oxygen is also administered to patients.

The sooner thromboembolytic drugs can be given, the greater the chance of reducing the amount of damage to the myocardium. The ideal is twenty minutes from onset of symptoms, and a first aid measure that can be given before arriving at hospital is aspirin (Pearson, 1999b). Indications for receiving thromboembolytic therapy are that it is less than 12 hours since the onset of pain, and/or using GTN has not relieved chest pain, and/or ECG changes are suggestive of an MI (Pearson, 1999b).

Further tests, which can be done later to assess the amount of damage, include echocardiogram, coronary angiography and exercise/stress tests (Pearson, 1999a). These also help to predict risks of the person experiencing angina, the chances of returning to an active life and whether surgery is required. If surgery is required, this is done at a later date and consists of coronary bypass, where veins or arteries are taken from other parts of the body and attached to the heart to bypass the damaged arteries. Once patients in New Zealand have been hospitalised for a heart attack, they are started on a cardiac rehabilitation programme as recommended by the NHF (1997).

NEW ZEALAND CARDIAC REHABILITATION PROGRAMMES

The NHF (1997) has produced a directory containing policy statements, minimum standards for cardiac rehabilitation and phases of cardiac rehabilitation. It also lists hospitals and centres offering cardiac rehabilitation programmes and support groups. The NHF acknowledges that some areas do not yet have structured programmes, but both the sites included in this study have programmes containing the recommended content. The recommendations of the NHF are that cardiac rehabilitation is based on:

- Physical activity and exercise
- Education about the disease, its treatment and prognosis
- Facilitation of psychological adjustment
- Addressing questions and providing help with social concerns
- Long-term lifestyle changes to minimise the risk of further cardiac events (Allison, 1997, p.56)

Whilst these recommendations remain the main focus for health professionals working to achieve government targets, the priority for patients is in their struggle to adapt to a new situation, particularly once they are discharged. There is evidence that psychological and social adjustment is linked to the information they receive which in turn impacts on their coping strategies (Keckeisen & Nyamathi, 1990).

Cardiac rehabilitation programmes in New Zealand are divided into three phases and the role of each is given below in accordance with the NHF (1997) recommendations.

- Phase 1 – inpatient. This phase begins as soon as the patient is symptom free and able to start discussing their condition. The programme should help patients begin to develop an understanding of heart disease, assist in physical and psychological recovery, provide information about risk factors and their modification, and increase the patient's sense of control.
- Phase 2 – outpatient. This phase begins as soon as possible after leaving hospital and continues up to the time optimal activity levels are resumed, usually between six and twelve weeks. The length of the programme depends on the specific needs of the patient and their particular cardiac problems.
- Phase 3 – maintenance, which is community based. During this phase, participants are encouraged and assisted to take responsibility for their own rehabilitation, dietary and lifestyle modification. This phase is not covered in this study.

INFORMATION ABOUT THE STUDY

Two sites were used for the study. The original site was chosen because of the involvement of the local Heart Foundation group, while the second site was chosen because of interest in the study and plans to reorganise the cardiac rehabilitation services in the future. Site one appointed a cardiac nurse educator shortly after the study began and on this site other health professionals lead the cardiac rehabilitation programme. On site two, there are two cardiac nurse educators who lead the programme.

Apart from organising cardiac rehabilitation programmes, both sites have an Intensive Care Unit (ICU) or Coronary Care Unit (CCU) for the early stages of treating coronary patients. There are different entry criteria for the cardiac rehabilitation programmes, but both include patients who have had a heart attack. Both sites have a six-stage treatment plan that enables patients to work towards discharge (see Appendix A). Patients also receive educational advice from health professionals, which often starts from the day after admission and is centred on risk factors.

Type of research

A qualitative, descriptive study was undertaken to see what information New Zealand patients and partners want following a heart attack. Local branches of the NHF in the two geographical areas helped towards funding and were very supportive of the research being undertaken. Thematic content analysis was used to interpret the data and resulted in four main themes being identified as significant to participants.

SUMMARY

Despite a significant decrease in IHD in New Zealand since the late 1960s (WHO, 1997a) the disease remains the leading cause of mortality and when combined with stroke patients, accounts for the highest number of hospital discharges. In terms of the mortality and morbidity rates, and the resulting health care costs, IHD is an expensive illness for New Zealand in terms of both the impact on people and finance (MOH, 1997).

A critical factor in the recovery process is reducing the damage to the heart by starting treatment as soon as possible after the onset of pain (Pearson, 1999b). Cardiac Rehabilitation programmes in New Zealand should aim to reduce risk factors by encouraging lifestyle changes in patients, while also addressing psychological and social issues on an individual basis to facilitate patients in the recovery process. This would be in line with the recommendations of the NHF (1997).

Chapter 2

LITERATURE REVIEW

INTRODUCTION

In researching the question of what information patients and partners want following an MI, it is necessary to review the literature relating to cardiac rehabilitation and specifically the cardiac education content that is designed to give formal and informal health education. Cardiac rehabilitation is a health promotion strategy and as such the educational component should involve working with and empowering people (WHO, 1997b). Existing literature suggests that many cardiac education programmes employ the traditional educational approach, in which patients and partners are given information and not surprisingly, their information needs are not always met (Chan, 1990; Dickerson, 1998; Wellard, Turner & Bethune, 1998).

An MI is a major life event, following which patients and partners have to try to cope with a new situation. One essential tool to assist with coping is provision of information relevant to that individual. Whilst nurses figure as a main source of information, there are calls in the more recent literature, to expand this role and ensure that nurses have the skills to facilitate participatory education models, and empathise with patients and partners (Benson & Latter, 1998; Gulanick, 1998; Price, 1996).

HEALTHY LIFESTYLE

In New Zealand, one aim of cardiac rehabilitation programmes is to provide health education and information to patients and their families following a heart attack. This is part of an overall strategy that will be discussed further on in this chapter. The information is based around recognition of risk factors for IHD and what is termed 'healthy lifestyle'.

In the Western world today, there cannot be a person who is not familiar with the term of 'healthy lifestyle' and this term opens up the whole debate on what does the term health mean? This is not the main focus of the study, but it does highlight a problem with the phrase 'healthy lifestyle'. Ideas on what is 'healthy' are likely to vary between different groups such as health professionals and patients and with individuals will vary according to their own circumstances (Ewles & Simnett, 1999). Factors that can impact on health include social, environmental and cultural influences and are not always within the control of the individual (Ewles & Simnett).

It is probably true to say that for the majority of people in the Western world today the term 'healthy lifestyle' conjures up pictures of people who exercise, don't smoke, drink in moderation and have reduced saturated fats and sugar in their diets. This is because the most prominent health promotion strategies are based around achieving a healthy lifestyle by controlling these areas, which are identified as risk factors. Risk factors are presumed to increase the chance a person has of developing a disease and contribute to the severity of the disease, as shown by the definition in Chapter 1. There is an expectation that individuals will take responsibility for modifying risk factors.

Lifestyle and health are affected by other factors already mentioned and over which individuals have little control (WHO, 1997a). Additionally, lifestyle is undergoing dramatic changes in many parts of the world, adding to the difficulties for individuals to maintain the healthy lifestyle that is advocated (WHOa). Technology has brought with it a faster pace of life, resulting in more stress, less exercise, fast foods and less time. This is what is referred to as a 'sick society' (Ewles & Simnett, 1999, p.7) and staying healthy within this environment is not easy. Reduced income for the elderly and unemployment are some of the contributory factors to a sick society and these have the effect of increasing stress levels. The main drive behind health promotion in relation to IHD is to reduce the incidence of IHD globally by promoting healthy lifestyles and reduction of health inequalities between different groups and communities (WHO, 1997a).

There are two distinct groups who can be targeted to make improvements in their lifestyle, those who have never had a heart attack and those who have. This study concentrates on the second group of people, not in terms of changes made, but the information they receive which is provided in anticipation of the individual making certain lifestyle changes by reducing recognised risk factors thus reducing their chance of another MI.

RISK FACTORS

Cardiac risk factors are divided into two groups the first of which are modifiable, which it is believed can be changed or controlled. Within this group, the MOH (2000) makes a further sub-division into firstly lifestyle behaviours, which include smoking, alcohol, diet and physical activity. The second sub-division is physiological factors that include diabetes, obesity and hypertension. In fact, the physiological factors are often associated with the effects of the lifestyle behaviours.

The second group of risk factors are non-modifiable, and include sex, age and/or family history of IHD (Zerwic, King & Wlasowicz, 1997). Of interest for people using the term risk factor, were findings by Turton (1998). In a pilot study for research into the information needs of patients and spouses following an MI, he found that even in this day and age, some participants in his study did not fully understand the term risk factor. As a result, in the final research, the term lifestyle factor was used instead. The idea of risk for individuals is disputed by Nettleton (1997), who describes risk factors as probabilities taken from studying a population. Her theory has implications for the present emphasis in health education on individual responsibility for reducing risk factors, especially if these are not the cause of their heart attack, and the lifestyle changes made do not prevent further heart attacks occurring.

Another risk factor is psychological stress. Apart from some of the sources of stress already mentioned which are physiological, stress may have psychological causes and be specific to an environment such as home or work. Additionally, there is now recognition of a specific personality known as Type A (Kingsley & Gupta, 1992), who is competitive, aggressive and constantly active, increasing the risk of high stress levels. The risk associated with prolonged stress is of a heart attack precipitated by high blood pressure.

Sex as a risk factor

Historically, IHD has been associated with middle-aged men (Jensen & King, 1997). The WHO (1997a, p.42) describes this belief as "a dangerously misleading picture – dangerous, most of all for women". More recently, people are beginning to recognise that post-menopausal women are also at risk of IHD (Jensen & King; Martin, 1998). Martin, who works for the WHO, states that in parts of the world, IHD is the most common cause of death in women of any age, but that there is a surprising variation in these figures between populations.

A ten-year study in Auckland from 1984-1993 showed that in the 35-64 age group, 345 per 100,000 men had an IHD event, which was mostly an MI against 92 per 100,000 for women. Women, however, were more likely to die following the event. The IHD rate did decrease over this time span for both men and women, which was accounted for by improved medical treatments and improvements in risk factor prevention (MOH, 2000). This report does acknowledge that association between all the risk factors and developing a heart attack have not been full investigated, and also report that there are differences in the relevance of some of the risk factors according to gender. That there are differences in the significance of some risk factors between women and men is supported by Jensen and King (1997) and Johansson, Vedin and Wilhelmsson (1983), and has implications for information given to men and women after an MI.

After menopause, the risk for women of IHD increases and in New Zealand, "coronary heart disease is the leading cause of death for non-Maori men and women from the age of 65 upwards" (Hay, 1996, p.3). If the ten-year study in Auckland, previously mentioned, had included people over 65 years, they may well have found more women having an IHD event. This same report shows that for Maori men and women IHD is the leading cause of death from 25 and 44 years of age respectively. New Zealand MOH targets to reduce these figures depend largely on educating people to successfully reduce modifiable risk factors. To understand the emphasis placed on this it in necessary to look briefly at the history of health promotion and how it evolved into the models of today.

THEORIES OF DISEASE

In any area, theories evolve and change reflecting beliefs, scientific findings, cultures and societies in which they operate. Two theories of disease that predominate in the world today are the lifestyle theory and the socio-structural theory. The lifestyle theory, which predominates at the moment, suggests that IHD is caused by "unhealthy personal behaviour factors" (Beaglehole & Bonita, 1994, p.61) and that these are under the control of the individual. Whilst some modifiable factors come into this category, not enough account is taken of socio-economic status that may affect the ability of people to make changes (Beaglehole & Bonita) or indeed the increasing evidence that in some people genetic make-up predisposes to causative factors such as diabetes and high levels of cholesterol (WHO, 1997a).

The socio-structural theory expects individuals to take responsibility for their own health, but the broader social responsibility of governments also features (Beaglehole & Bonita, 1994). The theories of disease presently contribute to the blame that health care workers often attach to patients who fail to adopt a healthy lifestyle and may well account for the way patients blame aspects of their lifestyle for their MI. Economic and political considerations influence the role government takes in discouraging people to partake in activities recognised as modifiable risk factors.

In New Zealand there is legislation controlling age limits for buying tobacco and the numbers of cigarettes that can be sold in a packet, and tobacco companies are banned from offering incentives to retailers selling their products (Booth, 1998). More recently, there are moves afoot to ban all smoking in restaurants. Restrictions and change within the beef and dairy industries, which form a major part of the New Zealand economy, have not been as rapid or marked, although low fat alternatives, such as low fat milk and cheese and lean cuts of meat , are now more readily available. 1996 figures for New Zealand show smoking as the risk factor with the highest overall cause of mortality in men and women (MOH, 2000). The socio-structural and lifestyle theories are the building blocks for the present day health promotion initiatives.

HEALTH PROMOTION OR HEALTH EDUCATION?

In the Ottawa Charter (WHO, 1986) health promotion is defined as "the process of enabling people to increase control over, and to improve, their health" (WHO, 1986, p.1). Whilst health promotion and health education are often used interchangeably in existing literature, health education is in fact one section of the much larger health promotion model. There are five strategies for successful health promotion as defined in the Jakarta Declaration of Health Promotion into the 21st century (WHO, 1997b) and these are to:

- Build public health policy
- Create supportive environments
- Strengthen community action
- Develop personal skills
- Re-orient health services

The WHO (1997b) state that these strategies are essential elements of health promotion and where all five are used in combination, programmes are more effective than ones where only one or two strategies are used. The Jakarta Declaration also states, "access to education and information is essential to achieving effective participation and the empowerment of people and communities" (WHO, p.3). Part of people achieving participation and empowerment depends on health care professionals focusing on the individual as a whole and embracing all their needs. It can also be seen that while health education is a critical area, it is a small part of a much larger plan. The Jakarta Declaration calls for more involvement from governments and health professionals, including breaking down of boundaries between agencies, more financial investment, empowerment of individuals and research into existing strategies to see which are the most effective (WHO). This shift in emphasis towards more global responsibility, modifies the very strong present influence of the lifestyle theory of disease, particularly as the Jakarta Declaration stresses that the best chance of successful health promotion strategies are ones which embrace all these components.

Two models of health education are identified by Latter, Macleod Clark, Wilson-Barnett and Maben (1992) the traditional model and the participatory model. The traditional model focuses on disease prevention and physical health, while the participatory model aims to assist people to identify their own health needs within a broader, holistic framework. Piper and Brown (1998) describe the traditional model as the patient information model, where patients are given information, and the participatory model as the patient empowerment model, in which patients are active partners in the education process. Many health education strategies aimed at encouraging healthy lifestyles consist of information and education by various health professionals, the mass media and health information leaflets. This approach, which follows the traditional model of health education, is referred to as "social marketing" by Lefebvre (1997, p.108), and the information provided is aimed at influencing people to modify their personal behaviour, as identified earlier by Beaglehole and Bonita, (1994).

A major part of health promotion initiatives relating to IHD are cardiac rehabilitation programmes that include health education, but the literature suggests that many of these use the traditional or patient information model for informing patients (Chan, 1990; Moynihan, 1984; Murray, 1989; Newens, McColl & Bond, 1997). This is not generally in line with the Jakarta Declaration

(WHO, 1997a), which states that health promotion should not be carried out to or on people, but by or with them.

WHAT IS CARDIAC REHABILITATION?

The WHO defined the goals of cardiac rehabilitation as aiming to:

- Improve functional capacity
- Alleviate or lessen activity related symptoms
- Reduce unwarranted invalidism
- Enable the cardiac patient to return to a useful and personally satisfying role in society (WHO, 1997a, p. 43).

The overall aim of the WHO (1997a) relates to improving world health and global reduction in IHD. It seems likely that the WHO goals would match those of patients who have experienced an MI, and also their families. This type of rehabilitation can be achieved "in societies with minimal medical personnel and equipment resources" (WHO, 1997a, p. 40), yet the Jakarta Declaration (WHO, 1997b) states that increased investment is one of five essentials necessary to achieve health targets. The words 'enable' and 'help' do at least hint at a partnership between health professionals and patients, and a move towards patient empowerment. As is shown in the literature this is not generally occurring at this time, although there are now some voices calling for change, (Price, 1996; WHO, 1997a; Wiggins, 1998).

Other definitions of cardiac rehabilitation that exist include;

- "to help patients achieve a physically active lifestyle, including return to work and to reduce the risk factors for coronary artery disease such as smoking, hypertension and hyperlipidaemia" (Noy, 1998, p.1033).
- "all measures used to help cardiac patients achieve an active and satisfying life and to establish a basis for long-term secondary prevention" (NHF, 1997, p.3).
- "To deliver information patient's need to modify their lifestyles" (Chu Lai & Cohen, 1999, p. 64).

These definitions vary in their emphasis. Noy's definition strongly favours risk factor reduction without including other factors that may impact on patients, and the wording is medically focused. Chu Lai and Cohen emphasise the need to provide information that patients require to modify their lifestyles. They base their programme on adult learning principles focusing on individualised content, and also helping patients to "identify their barriers to behaviour changes" (p. 64).

Cardiac rehabilitation should involve assisting patients to achieve a good quality of life after a heart attack as suggested in the definitions of the NHF (1997) and a part of this process is cardiac education as recognised by Newens, et al. (1995). Interestingly no mention is made of the families in these definitions, and yet the role of partners in facilitating the recovery process is recognised as pivotal (Dickerson, 1998; Thompson, & Cordle, 1988) and depends on them having information to do this. As the focus of this study is information given to partners and patients, it is the education part of the cardiac rehabilitation process that relates to this study.

CARDIAC EDUCATION PROGRAMMES

Working within the lifestyle theory of disease, risk factor modification forms a major part of the cardiac education programmes, and there is a medical emphasis in the aims of cardiac rehabilitation. Literature relating to the success of these cardiac education programmes judges them on lifestyle changes achieved (Chu Lai & Cohen, 1999; McSherry, Benison, Shaw & Davies, 1999; Steele & Ruzicki, 1987; Wiliamson, 1997). Indeed Steele and Ruzicki's work was prompted by a challenge at a conference to prove the worth of the programme by involvement in it "becoming a factor in length of stay reduction" (p.306).

Programmes based on the lifestyle theory are described by Tannahill (1997) as the risk factor orientated models of health promotion, a criticism being that they are dominated by experts (medical personnel) rather than being participatory with the patients. This does not fit with the patient empowerment model suggested by Piper and Brown (1998) and Tones (1991) as an effective health education model. The NHF (1997) aims for New Zealand cardiac rehabilitation programmes to involve patients in their own rehabilitation process, which is in line with the patient empowerment model.

An additional issue relating to the aims of cardiac rehabilitation is how effective lifestyle changes alone are in reducing IHD. Long-term lifestyle changes are reported as reducing the rates of atherosclerosis in coronary arteries and thus patient outcomes (Ornish et al., 1990). One author concludes that lack of exercise alone had little impact on mortality and morbidity relating to IHD (Brennan, 1997). His report reviewed several cardiac rehabilitation programmes and found an inordinate amount of time and effort was spent concentrating on one risk factor, lack of exercise. This leaves little room for meeting individual needs and it also raises the question of how people who have already adjusted their lifestyle or cannot identify any modifiable risk factors to change will feel about cardiac rehabilitation.

In his review, Brennan (1997) reported on research studies into the effectiveness of exercise and stress management in reducing IHD and concluded that many of them have "numerous methodological problems which constrain the generation of definitive conclusions for use in clinical practice" (p.697). In other words, the research supporting specific lifestyle changes to improve outcomes for cardiac patients is not conclusive. Exercise programmes in particular appear to only be effective while the programme lasts.

This raises another issue with cardiac rehabilitation programmes, as there is evidence that people do not continue with lifestyle changes once cardiac education stops (Brennan, 1997; Currie, Amos & Hunt, 1991). One of the lifestyle changes people do not maintain is exercise (Pentecost, 1992; Salisbury, 1995) and if people fail to maintain lifestyle changes, the aims of cardiac rehabilitation are unlikely to be met. The recommendation for a minimum amount of exercise a week, which represents the threshold for determining physical inactivity, is 2.5 hours of brisk walking (MOH, 2000).

There is recognition that the present situation is far from ideal with regard to how health promotion is delivered and its impact on whether or not people make lifestyle changes. One problem is over-emphasis on certain risk factors identified by Nettleton (1997, p.319) as the "holy trinity of risks", and these are a high fat diet, lack of exercise and smoking. She goes on to say these three areas receive "a disproportionate amount of attention" (p.319), particularly as the evidence on casual links is not absolute and health promotion programmes are often designed with little consideration of existing research.

Another issue is the approach taken by many of the programmes. In 1997 the WHO found that disease specific programmes are normal in the majority of countries. Because of the theories and models on which they are based they inevitably lead to viewing the body as "the enemy" (Caraher, 1994, p.466). The WHO (1997a) now recommend the development of integrated packages and state that there is "an urgent need to develop and incorporate activities that raise awareness of and motivation for healthy lifestyles and the environment to support them" (p.129). More recent programmes such as the one described by Chu Lai and Cohen (1999), in which patients are also encouraged to recognise barriers to change, may be more effective at promoting more permanent lifestyle changes, and more in line with the recommendations of the Jakarta Declaration (WHO, 1997b).

Changes in how cardiac education programmes are delivered are also being advocated elsewhere (Moore & Kramer, 1996; Nolan & Nolan, 1998; Normington & Goodwin, 2000). One suggestion is for liaison with local gyms and leisure centres to facilitate referral and encourage continuing activity (McSherry et al., 1999). In New Zealand, many such facilities already have exercise classes for people over 50.

Gulanick (1998) builds on this and emphasises the need for ongoing support and counselling, rather than short-term single risk factor education. While reducing risk factors remains a main aim, the need for motivating and supporting patients is acknowledged. This involves working with patients and involving them in the education process.

PATIENT INFORMATION NEEDS

A study involving five hospitals in the United Kingdom in 1995 found that following an MI, patients were generally provided with written information, and that health education provided by nurses took the form of giving information. Noted exceptions occurred where there were cardiac rehabilitation nurses, and in these cases more patient/nurse contact occurred (Newens, et al., 1995). Whilst many in cardiac education would say that patients are active participants in the programmes, Caraher (1994, p.466) argues that nurses are paid to teach patients "to reach an accommodation with their social and economic circumstances rather than educating them regarding social and economic causes of health". This represents the traditional approach with emphasis on individual responsibility following information giving, not individual advice. Caraher suggests that the presence of a dedicated rehabilitation nurse results in a participatory model of health education, which is preferable and more likely to result in favourable outcomes for participants.

The reports cited earlier which found information giving was the usual educational method also reported on the lack of individual assessment and planning with patients (Chan, 1990; Moynihan, 1984; Murray, 1989; Newens, et al., 1997). The majority of these studies are quantitative and were undertaken while patients were still in hospital, and with the exception of Chan (1990) who included women, involved only English speaking men. Although these studies excluded ethnic groups, illiterate adults and poorly represented women, with the exception of Murray the authors concluded that the information needs of patients were being met.

Murray (1989) stated that a significant number of patients felt information and advice given was not specific enough or relevant to their own needs. From all these studies, four main areas emerged relating to cardiac rehabilitation, these were:

- Patient education is needed for health /lifestyle changes to be made.
- Education needs to include individualised assessment and planning with patients.
- Formal teaching is more effective than informal for imparting knowledge.
- Nurses provide most of the education.

Self-perceived needs of patients

In all the quantitative studies quoted above, research questions were based on risk factors in line with lifestyle theories. This approach fails to give patients a chance to air their own views on what may or may not be important to them. Whilst many programmes now have sessions and videos specifically explaining the anatomy and physiology of the heart, it is likely that the 'how it happens' is not as important as the experience to the patient (Chan, 1990; Duryee, 1992). In a review of the literature published in the period 1975-1989 one of the areas addressed by Duryee was information patients identified as most important to them. She found that for the patients, risk factors and how to manage chest pain were ranked higher than understanding why the heart attack had occurred.

Many of the studies in the review were quantitative, and data collected was based around questions relating to risk factors, giving participants little scope for identifying their own needs. Of the small number of studies done using qualitative methods, one found that "the most important perceived learning needs of patients at hospitalisation and follow-up clinics are those that affect survival" (Czar & Engler, 1997, p.109). These include pain control, dealing with shortness of breath and what to do if symptoms recur and are very different to the information provided to patients under the risk factor model of health promotion. Duryee (1992) quoted two studies that identified differences in perceived information needs between nurses and patients, findings endorsed by

Turton (1998). This literature review appears to support the suggestion that in some areas, cardiac rehabilitation is not meeting information needs of patients, which may well impact on whether or not they make or maintain lifestyle changes.

How to provide information

The majority of information provided to patients is written, and Phase 2 of the cardiac rehabilitation programme depends on patients attending group sessions. One of the most comprehensive surveys that focused on the learning needs of 125 IHD patients was done by Merritt (1991). In this study, patients demonstrated a preference for organised sessions that included oral and visual teaching aids. Merritt wanted to study how people learn rather than evaluating the quality and quantity of learning. She also highlights the very relevant issue that although many studies show shortfalls in the knowledge received through patient education, very little attention has been given to individual learning styles. It is interesting that learning styles is addressed by Chu Lai and Cohen (1999) who incorporate adult learning strategies into their cardiac education programme. Of particular relevance to cardiac education programmes was their finding that in patients undergoing these programmes, preference for reading was significantly lower than listening, and that some people avoid group learning sessions. An additional issue with reading is that it assumes a good literacy level in English. Several Maori and other language brochures in IHD and risk factors do now exist in New Zealand, but there are not as many as the English ones, and again presume that people can read.

In New Zealand, Allison (1997) justifies the large amounts of written information patients receive as needed because of the shorter hospital stay. In other words patients cannot be provided with the same level of verbal information as they were previously, when they stayed in hospital for several weeks. Chan (1990) uses this same argument to stress that inpatient information "must be streamlined to cover only the information viewed by patients themselves as important as well as realistic for them to learn" (p.1144). Participants in her study identified early convalescence as a prime time to be educated, yet in the past this was often a time of hiatus before entering Phase 2 programmes. Given some of the results in research relating to written material, there is a possibility that much of it is not read.

One study which looked at Phase 1 and 2 of the cardiac education programmes, concluded that patient outcomes were improved when patients received the information as they asked for it, and were allowed to participate in their care by taking responsibility for and assisting in decision making (Wiggins, 1998). A potential problem with this model could arise with patients who do not seek knowledge, either because they are in denial about their illness (White Robinson, 1999), or because they simply do not know what questions to ask.

While recovering from an MI patients and partners are in a major process of adjustment. Not achieving treatment goals can be seen by the medical staff and patients as failure and may increase patient uncertainty and as has been shown these treatment goals include making lifestyle changes. Failure to encompass the patient's own perceptions and needs and concentrating only on physiological factors is likely to reduce the effectiveness of educational strategies (Price, 1996) and may prolong adjustment to the changed situation.

When to provide information

Adapting to life after an MI is a major change in people's lives. Trying to cope physically and psychologically with this change must affect the ability to absorb and retain information. Authors who acknowledge the importance of keeping Phase 1 streamlined to realistic amounts of information, which in turn is viewed by the patient themselves as relevant include Chan (1990) and Steele and Ruzicki (1987).

The studies discussed in this section concentrate on information patients want in the hospital period and acute phase of illness and this information may differ from what they want once home. Indeed a succinct comment provided by one of the participants in Murray's (1989, p.691) research puts this difference into perspective when he stated "It begs the question of how you feel about the information if, when at home you find you haven't been given enough information". Partners of patients who have had a heart attack also want information to help them adjust to a new situation.

PARTNERS' INFORMATION NEEDS

There is a lack of literature relating specifically to the information needs of partners of patients who have had an MI, although Dickerson (1998) identifies that seeking information is a way for partners to deal with the uncertainty of their situation. Studies tend to concentrate on social and/or psychological support for partners, examples being Hilbert, (1994), Thompson and Cordle (1988) and Thompson et al., (1990). Of these studies, one included wives and the second, husbands and wives, although with a greater ratio of wives to husbands (Thompson & Cordle: Thompson et al.). This focus narrows the specific interpretation of partner that does not represent the more diverse and varied partnerships that exist today. Both Hilbert and Turton (1998) included any partners, but the participants were all heterogenous couples. Turton acknowledges the small size of his study that has implications for generalising the findings to larger populations.

One of the findings was that many wives felt they received enough support during and after their partner's heart attack, but significantly most of the support was from relatives and friends, not medical or nursing personnel (Thompson & Cordle, 1988). Dickerson (1998) found that partners' needs were often overlooked in favour of staff meeting the patients' needs. There was a high percentage of participants who felt they had not had their information needs met, and 63% felt that they had not had enough opportunity to ask about the heart attack and ongoing care (Thompson & Cordle). Whilst the patients' needs are paramount, meeting the information needs of partners has been shown to impact on the support they are able to offer patients, which in turn has an influence on the recovery process (Beach et al., 1992; Dickerson, 1998).

Partners identified the two times they most sought help was on hospitalisation and immediately after discharge. In one study, partners reported that CCU staff did not always treat them as active partners who had a role to play in the recovery process (Coyne, & Smith, 1991). Participants in Dickerson's qualitative research (1998) were all wives, and reported that discharge was a frightening time, as the responsibility for the patient suddenly became theirs. They sought information that removed uncertainty on issues such as behavioural change and symptoms, and which would enable them to identify what was normal and what was not and would therefore improve their ability to cope with the new situation.

The participants in this research (Dickerson, 1998, p. 17) identified a "helpful person", who had helped them simply by being available. This was defined as a person who had "an objective view of the situation that allowed the spouses to gain perspectives that could facilitate problem solving". This person spent time listening and was not always a health professional. Dickerson takes the view that health care providers should be given education to enable them to meet this role. Additionally, in line with other research, while some partners were able to verbalise their needs for information, many had problems communicating and thus received less information (Dickerson; Coyne & Smith, 1991). Information has a direct effect on how people cope, and the processes of adjusting and coping are closely linked (Keckeisen & Nyamathi, 1990).

COPING AND ADJUSTING

The process of adjustment that follows any major event, and a heart attack is one example, requires patients and partners to cope with the new situation. Coping is described as "the process by which people try to manage the perceived discrepancy between the demands and resources they appraise in a stressful situation" (Sarafino, 1990, p.145). He goes on to point out that coping strategies are varied and while aimed at mastering the problem do not always achieve this. Coping strategies may, however, help the person live with, escape or accept the situation.

The two main ways of coping are described as emotion focused, in which people search for ways to reduce the emotional stress; and problem solving, in which choices are made to change something in a person's life. These can be employed independently or together. In their research study of 30 participants linking coping and adjustment, Keckeisen and Nyamathi (1990) reported that those who used more problem-focused coping, adjusted better in both the psychological and social areas one month after discharge, than those who used emotion focused coping. Both coping methods rely on people having information that is relevant to their needs, and social support.

A 1990 study used control and experimental treatment groups to test if there were benefits of structured counselling for wives in helping them to cope after their husband had had an MI (Thompson et al., 1990). Although initially the differences were not marked, after six months, the treatment group remained confident, more satisfied and less anxious than the control group. Dickerson (1998) found that in partnerships where patients and spouses attended cardiac rehabilitation classes together, they had a more hopeful perspective on the future. Based on her findings, and those of other researchers, Dickerson advocates that spouses should be referred to support groups early in the illness and nurses develop the skills to meet the need of partners at this difficult time of major adjustment. The importance of the role of nurses in the period following a heart attack is further supported by Newens et al. (1995) and Nolan and Nolan (1998), the latter having carried out a literature review of cardiac rehabilitation programmes.

THE ROLE OF NURSES AS EDUCATORS

Nursing staff are cited as a good source of information in some studies (Murray, 1989; Noy, 1998; Dickerson, 1998), although Tilley, Gregor and Thiessen (1987) found medical staff the preferred source over nurses, as information from the latter was reported to be unclear and inconsistent. There is evidence of nurses teaching by "a nursing determined rather than a patient needs approach" (Wellard, et al., 1998, p.16) which is the traditional approach

approach identified by Latter et al. (1992). Wellard et al. also point out that this often occurs because the medical diagnosis has shaped the education provided. A selective review of the literature looking at nurse/patient communication, describes nurses as controlling and leading the conversation (Jarrett & Payne, 1995). The authors point out that more research is needed from the patient's perspective, as most studies focus on the nurse.

One problem is whether nurses are adequately prepared for this educational role, in which they play a main part. Benson and Latter (1998) stress the importance of nurses acquiring skills to promote holism, collaboration and individualisation rather than the prescriptive traditional approach to health education. Given that nurses provide the most information to patients, it is important that nurses are able to empathise with the patient's experience (Charmaz, 1995; Price, 1996). Price challenges nurses to understand, assess and teach clients about the altered physiology of the body, but also to understand the experience of this as described by the patient and his or her family. Research supporting the need for nurses to understand the meaning of the heart attack for the spouse, if they are to be effective in helping them, is provided by Dickerson (1998).

A recent Australian study on nurses as patient teachers cites problems for them trying to teach and being caught between "the health promotion empowerment framework and mechanistic–interventionist framework" (Wellard et al., 1998, p.12). Some of the problems for nurses trying to teach patients which were identified in this study include limited time and resources and poor interdisciplinary communication. They recommend teaching nurses about patient education at undergraduate and post-graduate level and that specialist roles, such as that of the cardiac education nurse, not only meet more patients' needs, but also provide support for ward staff in their efforts to educate patients. In her paper on the theory of uncertainty, Mishel (1990) says nurses need to move from the mechanistic to the probabilistic paradigm when dealing with patients who are ill. In other words, away from the scientific/medical model in which uncertainty has no place, to a theory in which there is acceptance that everything cannot be known. This shift in attitude would involve the nurse acquiring specific skills and being able to use them in practice.

Specialist nurse educators

Teaching should be a collaborative process involving both teacher and learner (Hinchliff, 1995) that facilitates the process of assessing, planning, implementing and evaluating what people hope to achieve. Developing these and other skills requires academic preparation and Gulanick (1998) recommends that this be at Masters level. Case management as a way of individualising education and information provided to patients is also advocated by Gulanick. She reports on an initiative underway in Illinois that identifies patient education as only the first step in the whole process of rehabilitation and stresses the need for ongoing individualised counselling and support. Graduate nurses are being offered a course in cardiovascular health and rehabilitation to equip them to undertake this continuing work in the community.

The emerging specialised role of nurses as cardiac educators appears to provide the opportunity for individualised care (White Robinson, 1999). Cardiac educators also seem able to bridge the gap in information that was occurring immediately after discharge before Phase 2 education began (Thompson & Cordle, 1988; White Robinson 1999; Wiggins, 1989; Wiliamson, 1997). Gulanick (1998) admits that the long-term aim of the cardiac rehabilitation programmes is promoting lifestyle changes that are maintained and intended to improve patients' outcomes. Moving to participatory models of health education appears to be the way forward, both in terms of meeting the information needs of patients and as a consequence potentially improving patient outcomes. Researching the question of what information patients and partners want following an MI should provide findings that will indicate whether participatory cardiac education programmes are practised in parts of New Zealand.

SUMMARY

The strong emphasis on the lifestyle theory of disease in the 1990s combined with the identification of specific modifiable risk factors for IHD has resulted in health education programmes that are driven by medical and nursing personnel, who in turn are driven by government and world targets aimed at reducing mortality and morbidity from IHD.

Varying definitions of cardiac rehabilitation highlight some of the confusion relating to whether patient education is a part of or the main focus of programmes. Additionally, existing literature shows that the traditional model of education is most commonly used in cardiac education programmes and that it appears to fail in both affecting long-term lifestyle changes and in meeting the individual needs of patients and partners following an MI. Information needs are linked to how people adjust following a heart attack and can impact on their coping mechanisms. Changes in how these programmes are run are advocated and these changes should also address the information needs of partners who play an essential role in the recovery of patients from MI.

The role of nurses as the main educators is constant throughout the literature, with the more recent recognition of the special skills needed to effectively function in this role. In the future, given the short hospital stay, and involvement of partners, it may be necessary to rethink cardiac rehabilitation programmes so that they have a wider focus than education relating to risk factors. This in turn may help both to achieve government health targets and involve patients and partners in the information giving process, so that they are able to adjust to their new situation and maintain lifestyle changes.

Chapter 3

RESEARCH DESIGN AND METHOD

INTRODUCTION

This descriptive qualitative study uses thematic content analysis (Burnard 1991) as a method for interpreting data provided by patients and their partners as they carry on with life after a heart attack, and identify their information needs. As qualitative research was undertaken, there is a necessity to establish the credibility of the research process (Sandelowski, 1986), and this is achieved by providing an audit trail. The audit trail gives insight into how I arrived at the themes finally identified, a process that required a paradigm shift from the nursing/medical perspective to a participant orientated perspective. Also included in this chapter is an examination of the ethical issues associated with completing this study.

THE USE OF QUALITATIVE RESEARCH

At first look, the research question appears to favour the quantitative approach, and indeed the great majority of surveys exploring this topic are quantitative, as shown in the literature review. Limits of the quantitative approach are recognised by Newman (1992) as discounting certain types of knowledge and revealing assumptions that may not be shared by all in that discipline. This often results from the rigid framework within which quantitative research is carried out. Examples in cardiac rehabilitation are studies providing lists of risk factors when looking at information needs of patients and/or partners, discussed in the previous chapter. In terms of theory building to expand the knowledge base of nursing science, qualitative research is most suited to focusing on the whole of the human experience which helps towards understanding human behaviour (Beanland, Schneider, Lo-Biondo-Wood & Haber, 1999)

A widely accepted reason for doing qualitative research is when little is known about the topic. Walton (1994, p.282) says that qualitative research can also be used "to offer a fresh perspective on an area which has previously been well investigated". That is the aim of this descriptive study; to go beyond lists looking at information needs and discover what information patients and partners want following a heart attack.

SELECTION OF PARTICIPANTS

Participants were selected from two different sites. The only selection criteria were that patients had had a heart attack (MI), for which they had been hospitalised, additionally, they needed to be English speaking. The criterion relating to a heart attack relied on a medical diagnosis of myocardial infarction appearing in the patient's notes. The cardiac nurse educator then had to identify these patients as potential participants. Not having a partner did not prevent a patient from taking part, and any partner of a patient could take part.

This did not have to be the patient's first heart attack, which many previous studies have stipulated. In this study, of eleven patients, eight had suffered their first heart attack, two their third, and one his second, although he had been unaware of his first one occurring. Interestingly, no major differences were identified in terms of the research findings, except that participants who had had a previous heart attack spontaneously engaged in comparisons between their previous experience(s) and the existing one.

Decisions about sample size in qualitative research are made in relation to theoretical saturation; that is when no more new information is forthcoming. Sandelowski (1995) argues that sampling size relates to number of interviews, observations and field notes as well as numbers of people and that researchers claiming theoretical saturation often have samples that are too small. Within the time constraints of this type of research (i.e. for completion of a degree) the reality is that there comes a time when one has to begin the writing up process providing one has reached apparent saturation.

Participants included six males and five females. Their age range is given in Figure 1. Six partners of patients also participated. Of the others, one never volunteered, one said she was too busy to take part and three patients did not have partners. The mix of partners was four wives, one husband and one sister. The introductory letter (Appendix B) asked for partners to take part and the sister, who lived with the patient, obviously identified herself in this role. One partner (male) was also included in some of the data relating to patients as he had had a heart attack the year before, and his wife used his hospital experience as a comparison to her own.

	40s	50s	60s	70s
Male	1	1	1	3
Female	0	1	1	3

Fig. 1 Age range of patients.

The selection criteria did not specify how long after having an MI patients were eligible to take part, and in hindsight, this may have been an oversight as there is a potential for different priorities to be identified by patients the further on they are from having their heart attack. Two patients were interviewed after they had had bypass surgery, while all the others had had their MI in the previous eight weeks. The interviews of these two post-surgical patients (one male, and one female) do not, however, identify any major differences; rather, they contain the same themes identified in the other interviews.

Accessing participants

Initially participants were recruited by placing a letter (see Appendix B) in their hospital discharge information inviting them to take part. This resulted in a very poor volunteer rate, and following return to ethics committees, it was agreed that the cardiac nurse educators would give patients the letter either in hospital or at home. This resulted in a better response, but is also an appropriate point at which to mention one of the "Ouch factors" in this type of research (Alty & Rodham, 1998, p.275). The O of ouch represents "overestimating the support and interest you might expect to get from other staff members" (Alty & Rodham, p.275) and this can lead to major problems accessing participants. As New Zealand ethics committees require an intermediary to initiate the recruitment process, participant numbers may be influenced by lack of support from intermediaries in the process.

In the case of this study, there were marked differences in the approach of the cardiac nurse educators. One was very keen on the study, and interested in reading the completed thesis. The other educator, while interested in the study, had other priorities, additionally she went off sick in the recruitment stage, and as a result I ended up with less participants from that area.

Other issues, which can arise with third party recruitment, are unintentional gate keeping where the third person selects (or rejects) participants they feel are appropriate (or inappropriate) participants. Rose (2000) identifies that this can occur as an act aimed at protecting the patient. Additionally, the attitude of the intermediary to the research, and the way they approach the participants may affect whether people volunteer or not. Interestingly, third parties who are the most helpful in facilitating access are nearly always well regarded by the participants (Rose). Depending on the topic being studied, this has the potential to affect the results of the research.

Prospective participants sent me back a return form (Appendix C) and I then contacted them and sent them an information sheet and one for the partner if required (Appendix D). One week later I contacted them again, and if they wished to continue, made arrangements for the interview to take place and the participants signed the consent form on this first visit (Appendix E).

Information sheets and participant selection

Recent research history in New Zealand has led to what could be described as erring on the side of caution when it comes to the issue of informed consent, and the information sheet is a case in point. Behi (1995) raises several issues relating to this such as how and to what level should participants be given information relating to informed consent, and do different groups e.g. staff, patients and carers need different types and levels of information?

Whilst the initial information sheet asking for participants is a single sheet, the information sheets supplied to patients and partners before they sign the consent are extensive and detailed and do not make it easy for participants to separate the 'want to know' from the 'need to know'. They preclude people who cannot read, or are not easy readers, and could even be daunting to a literate person adjusting to illness and feeling below par. In the case of this study, the result is that the very people who may not get their information needs met, given that much of the cardiac rehabilitation information is written, are excluded from the study. Specific issues relating to this research study are discussed in Chapter 8.

DATA COLLECTION

As the researcher in this descriptive study my aim was to find out what information patients and partners want following a heart attack. Of over–riding importance in qualitative research is that the information must reflect the actual experience of the participant and not be contaminated by the interviewer suggesting how the participants may have felt (Rose, 1994). Collection of data was by semi-structured interview, an essential part of thematic content analysis (Burnard, 1991).

Semi structured Interviews

This type of interviewing allows the researcher to focus on particular issues while still giving the participants freedom to raise events and feelings important to them (Polit & Hungler, 1985). Semi-structured interviews require an interviewer who is open-minded and can deviate from the planned pathway if that is where the participant wants to go. Rose (1994, p.25) describes this as "a step into the unknown, into the life and feeling of another human being".

Establishing rapport is essential if participants are to talk about their experiences. With multiple interviews there is more time to do this, but single interviews, which were carried out in this research, rely on some empathy developing in a short space of time. There were a couple of early interviews where I felt I failed in this by rushing into the interview, but learning from this, I spent longer on the introductions and preliminaries in subsequent interviews. I feel my age, years of nursing experience and familiarity in working with ill people also helped me in terms of my credibility to participants. Trust and rapport improve the "interpersonal encounter" (Lipson, 1991, p.75).

As the participants had volunteered, they obviously had an interest in taking part, and indeed I feel that for some they were glad of the chance to have a say. One partner (F8P) actually said *"And even in fact talking to you I think has been quite good."* One of the patients (M1) who had had problems having his information needs met said it had been a relief to talk to me.
In the first two interviews, the two opening questions were:

1. Is this your first heart attack or was this your partner's first heart attack?
2. What information were you given about you/your partner's heart attack?

Following discussion with one of my supervisors, we changed question one to: "Could you tell me what the experience of you/your partner's heart attack was like for you?" This acted as more of an icebreaker and started the participants off right away into detailing their experiences.

Responses to these questions shaped how the interview developed. I had cards with key points relating to information needs that I could refer back to if the interview digressed too far from the original subject. A final question which related to the aim of the study was "Was there any anything else you wanted to know that you weren't told?" if this had not already emerged during the interview.

Interviews were conducted in the interviewees' homes, and patients and partners were interviewed separately except in two cases where they requested to be interviewed together. Interviewing separately ensured that both parties felt free to express their feelings without the risk of upsetting their partners. Tea and biscuits frequently accompanied the interview process and lent an informal air to the proceedings.

Field notes

These are notes taken in the field that can help to set the scene of the interview and what was observed. They record the context in which data gathering occurs (Thorne, Kirkham & MacDonald-Emes, 1997). They can help to keep the researcher on track later on when looking at the transcripts. Taking notes during the interview did not seem appropriate in this study, so as soon as I had left the house and was in the car, I jotted down my observations, which then formed part of the audit trail.

There were also notes to myself such as; 'This was a much better interview I was not afraid of silences, remember this for future interviews'. My field notes in fact merged into memos at times, the main difference being that they were recorded immediately after the interview and did help link what participants said to how they behaved and their environment.

Note taking can be split into four categories (Richardson, 1994) and the first category is observational notes which are described as accurate observations during the research process, and this is what my field notes were. Methodological notes come second, which are messages about what to wear and when to contact people. Clothes and appearance can impact on the relationship between interviewee and interviewer (Rose, 2000). As I had two phone calls to make, one on receiving an expression of interest and one following posting of the information sheet, recording when to contact people was an essential part of the project, especially when I had three participants expressing interest in the same week. Additionally, several participants were very specific about the time of day they wished to be contacted.

The third category is theoretical notes, which are hunches, interpretations and critiques and comprise the largest section of my own notes. The fourth category is personal notes, looking at your own doubts and hopes. Whatever method of note taking is used, writing early is essential (Wolcott, 1994). Thoughts not recorded can be lost forever. Despite reading from several different sources the importance of being organised, I fell into the trap of scattering notes and memos. Initially I wrote on post-its and stuck them into the notebooks I was using. Then I wrote in the books, but in random places, with the result that one of my later memos said 'Find all the memos I've written', I then spent half a day doing this and transferring them onto the computer after which I allocated a note taking section in one notebook for all my thoughts.

Transcribing

This is the process of typing up the interviews and it requires an experienced typist, who signs a confidentiality form (Appendix F). Transcribing should be done as soon as possible after the interview. Once returned, I read the transcripts through and checked them against the tapes. During this process, any gaps or wrong words typed by the transcriber were altered or added in. More importantly I could ensure that any emphasis or pause in the interviews was accurately recorded.

An example of this was one participant who wanted to make four points that were very important to him. He emphasised them by enumerating a-d while at the same time forcefully recording them off on his fingers. I indicated this on the transcript when I went through it with my field notes.

Factors which could have an impact on the final interpretation of the transcripts include:

- Background noise on the tape

- Transcribers being unfamiliar with the topic and language, particularly medical terms or drug names in this case.
- Exclusion of pauses and word emphasis as discussed.

Of these, background noise proved a problem for part of two interviews, one while a kettle was boiling and one where the participant had a caged bird. The transcriber had to leave a few gaps in these places, but there was only one interview where I was unable to fill these for a couple of lines, as I could still distinguish what they were saying. The transcriber also left some blanks where medical conditions or medications were mentioned. These I completed from the tapes as soon as I received the transcribed interviews back.

In my first interview, I did not have the tape recorder near enough to the participant and as a result, some of the ends of sentences were lost. I did not repeat this error. Additionally, it was essential when using 30 minute a side tapes to ensure that the interview was stopped and the tape turned over at the correct time. Once each transcript was complete analysis of the data was begun. An essential element relating to the data in qualitative research is establishing credibility.

CREDIBILITY IN RESEARCH

Credibility is defined in dictionaries as being reliable and dependable. In qualitative research, investigators aim to understand a human experience and help others to understand it too (Ammon-Gaberson & Piantanida, 1988).

The final credibility check is that readers of the study, whether participants or not, should be able to relate what is written to their own experience (Cutliffe & McKenna, 1999; Sandelowski, 1986). The checks along the way depend on the researcher being clear about the method they are using (Ammon-Gaberson & Piantanida, 1988; Cutliffe & McKenna). Another essential is an audit trail (Avis, 1995; Koch, 1994).

In any interpretation there is the risk of the researcher altering the meaning of the content. The expectation that all influences and bias can be removed is naïve (Thorne et al., 1997). Personal beliefs and a nursing culture will shape questions and how they are asked, which in turn impacts on the final interpretation. An audit trail allows the reader to follow what happened and how and why the researcher arrived at their interpretations (Koch, 1994; Morse & Field, 1996). The audit trail for this study is provided further on in this chapter in the section 'working with thematic content analysis'.

THEMATIC CONTENT ANALYSIS

This study uses thematic content analysis as described by Burnard (1991). He used the grounded theory approach as described by Glaser and Strauss (1967) for his framework and has then incorporated the work of other researchers on content analysis. Grounded theory is "a general methodology for developing theory that is grounded in data systematically gathered and analysed" (Strauss & Corbin, 1994, p.273). An essential part of grounded theory is that researchers accept responsibility for interpreting the words of the participants. Wolcott (1994) goes to great lengths to differentiate between analysis as the breakdown of data and interpretation as a more creative and speculative process that creates meaning from the data.

Content analysis does not capture the context of what is being said, but is a way of analysing and isolating themes that can then be counted and interpreted (Denzin & Lincoln, 1994). A metaphor used to describe the emergence of themes likens it to picking threads from fabric (Ely, Vinz, Anzul & Downing, 1997). They define a theme as one that runs through most of the pertinent data, or one that, although in a minority, carries "a heavy emotional or factual impact" (Ely et al., p.206).

Interpretation is the time where researchers can be in danger of expressing their own views rather than those of the participants. To help overcome this it may be useful to follow Wolcott's (1994) suggestion that researchers must not use this stage to follow their own opinions, but must be able to make a clear link between their interpretation and the data. This should be done by using codes or themes identified in the analysis stage and by matching interpretations with descriptions as is done in thematic content analysis. Lists of codes and categories with no apparent link or relevance result in research reports that do the promotion of qualitative research a disservice (Sandelowski, 1998).

In some ways cardiac medicine not being my own speciality was an advantage, in that I did not have preconceptions on what participants would say or feel. Inevitably the literature review started to influence some of my thoughts, and it is for this reason that in grounded theory a literature review is not carried out before the study. The idea is to allow a theory or theories to emerge directly from the data collected (Beanland et al., 1999). Some of the issues relating to my own interpretive efforts are discussed in the following pages and also provide the audit trail for this study.

Another factor that may affect interpretation and is of relevance to this study is the use of language (Crowe, 1998). Descriptions and meanings will differ from participant to participant according to their sex, culture and age, and the researcher's nursing culture may impact on interpretation. Previous experience within the field being researched could affect how a person interprets data; in this study this risk is reduced, as it is not the specialist area of the researcher. Crowe identifies one of the dangers of interpretation as being when the researcher is seen as the expert in the area who then determines the "subject's interpretation of meaning" (p.341).

The process of thematic content analysis has fourteen stages and involves repeatedly returning to the data, including completed transcripts, memos and field notes to analyse and sort the contents into recurring themes and then interpret this data. Returning constantly to the original data source is essential (Burnard, 1991), and reduces the risk of sorting and coding instead of interpreting (Morse, 1994; Thorne et al., 1997).

WORKING WITH THEMATIC CONTENT ANALYSIS

Although Burnard (1991) describes the whole process as thematic content analysis, stage one to eight incorporates the analysis stage, while stage nine onwards involves interpretation. Stages eleven and twelve check on the validity of findings, stage thirteen is writing up, while stage fourteen describes two different ways of using the existing literature when writing up the findings.

Stages one to five

Stages one and two are the making of field notes and memos as already described and involve immersion in the data and recognition of general themes. Stage three involves writing down headings for all the contents, including fillers, which are content areas that do not fit into the topic. This is the beginning of identifying themes. Stages four and five involve collapsing categories down to avoid duplication.

Being new to this process, I initially struggled with these stages. I started with open coding the transcribed interviews and linking them in with data in the field notes and memos. As a novice, this was a painstaking process. This process involves the recognition and reduction of content and produced a wealth of topics. Despite the fact that I had asked for the participants' experience of a heart attack, I kept trying to relate all my early headings to information. Additionally, I tended to put my own nursing interpretation into the themes as shown in Figure 2.

Self diagnosis	Communication	Stress
Symptoms	Loss of control	Prevention strategies
Searching for a cause	Information sources	Adjusting
Women and pain	Health education	Voluntary lifestyle changes
Roles /partners	Frustration	Cardiac educators
Discharge communication	Not knowing	Information required
Dross	Involuntary lifestyle changes	Denial

Figure 2. First thoughts on themes

Collapsing the contents of the interviews provided me with three main areas: experiencing a heart attack; trying to make sense of a heart attack; adjusting to life after a heart attack. This still left me with chunks of data that did not fit into these categories. This was not irrelevant data, but data that would not fit. My supervisor suggested that I return to the data to see what my participants were telling me.

In spite of having the research question in front of me and bearing in mind the extra question relating to the experience of a heart attack, I was failing to identify what was happening from the participants' perspective. Additionally, I was concentrating more on content, which Morse and Field (1996) define as categories, than themes that are threads which run through the data and which can be abstract.

Stage six

Burnard (1991, p.463) describes stage six as an attempt "to enhance the validity of the categorising method and to guard against researcher bias". It involves colleagues generating category systems independently of the researcher. I relied on feedback from my two supervisors and a work colleague. This was where my nursing bias was identified, and one supervisor and my colleague suggested that although the subject area of the themes was sound, the emphasis needed to be more participant centred. Themes can be difficult to sort out and the researcher needs to step back and try to decide what the particular participants are trying to say (Morse & Field, 1996). This involved a paradigm shift away from a nursing focused perspective to a patient perspective.

The problem of how to look at something is compounded by the literature. As I started to code the participants' experiences of a heart attack, I began to search the literature with its emphasis on patients denying the occurrence of a heart attack and how heart attacks are dramatic, or sudden events. This re-enforced my nursing perspective. When I finally started to take note of what the participants were saying, I underwent the necessary paradigm shift and ended up with four final themes consistently represented by all participants. These fitted the data collected, except for the "dross" (Morse & Field, 1996, p.84) or irrelevant data, which was now far less than in the original analysis.

The four themes which were taken from words spoken by participants were: it wasn't too dramatic; they didn't even think it was a heart attack; tell me what my particular problems are and you just sort of box on. These themes still broadly matched the original three, but by taking the participant's perspective, experiencing a heart attack became two separate themes, the first one being 'it wasn't too dramatic' and the second 'they didn't even think it was a heart attack', which related specifically to the experience for women.

Stages seven to nine

These stages finalise all themes and sub themes. Doing these, I also followed Burnard's (1991) advice to highlight or colour code themes and sub themes. Once again, I interpreted rather than analysed, now that I had my thinking more in line with participants. For example, where I originally had a sub-theme of women and pain, in the final interpretation it became two sub- themes, as aspects of their pain led to them 'knowing something was wrong,' while 'trying to get pain relief' was what the women had to do. The final themes and sub-themes are shown in Figure 3 on the following page.

Stage nine involves cutting relevant themes out of each interview and putting them all together. It is essential here to retain and refer back to a full transcript, so that being taken out of context does not change meanings of words and phrases. I found myself doing this more frequently the further into the writing process I progressed. Because of the overlap that occurs in the adjustment process, some sections of text covered two of the three themes and were colour coded accordingly. It is also essential to label each cut out section with the participant's code, although I found that I could remember who had said what having lived with the transcripts for so long.

It wasn't too dramatic	**They didn't even think I was a heart attack**	**Tell me what my particular problems are**	**You just sort of box on**
Realising something is wrong	Knowing something is wrong	Failing to meet individual information needs	Adjusting to life after a heart attack
Deciding to seek help	Trying to get pain relief	I don't think I was told much	Somebody to talk to
How to seek help	Receiving a diagnosis	Being inundated with information	Searching for the cause of a heart attack
		Deciding whether to attend Phase 2 classes	Not being able to identify a cause
			It's not being able to drive
			It's a constant trek

Figure 3 Final themes and sub-themes

All the themes were phrases used by participants. My field notes re-enforced the themes, themes two and three producing a stronger response in terms of repetition or body language, an example being M1 who counted off on his fingers that he wanted to know by steps what he could do to help himself.

The main difference with these themes, as opposed to the first themes, is that they fit together, showing how patients and partners move through the experience of a heart attack, hospitalisation and recovery at home. It is difficult for them to know what it is they want to know until they return home to try to pick up their normal lives. The title or overriding theme came from feelings expressed by both patients and partners, is "They did explain everything, but I can't remember".

Stage ten

Burnard (1991), describes stage ten as pasting, which I did by clipping each whole theme together and ensuring sub themes were colour coded. This also helped retain larger chunks of text together, thus reducing the risk of losing the meaning and/or having to check back frequently to the uncut transcript. This was most useful in the early stages of the process.

Stages 11-13

Stages 11 and 12 are validity checks, and (F8P) stated *"We enjoyed the time you spent with us and I have been grateful for all the help given to me".* It is possible that when participants are used for validity, they will fail to offer criticism or alter themes if they feel this way, but the importance of using participants is supported by both Sandelowski (1986) and Stern (1999).

Two of the participants verified the final themes without making any major alterations or suggestions, one stating that she had not actually linked the fact that she was unsure how much she could do to a lack of information, but now realised that this was so. The other participant stated that although he had said he had received a lot of information, he now realised that some of his problems adjusting to a new lifestyle was because the information had not made it clear how much he could and could not do apart from walking.

In stage 12, Burnard again highlights the need to check back to the complete transcript or original tape. This I did, and it helps to ensure that the context of what was said has not been changed or lost in the interpretation. Stage 13 is the writing up process done section by section, or theme-by-theme. The final stage involves linking the findings to relevant literature.

Stage 14

The literature can be written up separately at the end of the study, or incorporated in the findings as the writing up is done. This thesis is written up using the second approach where the findings are presented alongside the existing literature. Burnard (1991) suggests that this method may not be as pure as the alternative of presenting them separately, but is more readable and also more practical to do.

ETHICS

The whole process of ethical approval is primarily to protect the participant. Ethical clearance was obtained from four ethics committees:

- The Polytechnic Ethics Committee (place of my employment)
- The two local Health Authority committees where the research took place
- Massey University Human Ethics committee.

It was interesting to note that all came back requiring minor changes to the information sheets, none of which were the same.

Informed consent

One rather lengthy definition of informed consent is that:

> A lay person may perceive informed consent to be a voluntary agreement, without any coercion to take part in research after one has been given, in comprehensible form, all the relevant information that may influence the decision to take part or not (Behi, 1995, p.15).

I felt that there were some issues relating to the provision of information in this study and these are discussed in Chapter 8. The use of a third person (the cardiac nurse educator) in the recruitment phase overcomes the problem of coercion, but opens the way for gatekeeping as discussed earlier in this chapter.

Confidentiality

Once the participants had agreed to take part in the project an appointment was made for the interview. The consent form (Appendix E) was signed on this visit after participants had been given the chance to ask any questions raised from reading the information sheet. All participants were asked whether they consented to the interview being audiotaped and informed that they could request the tape turned off at any time. No one refused to have their interview taped. All participants were given the option of having the tapes returned to them at the end of the project, but only one couple wanted this.

As soon as tapes were transcribed, all names and places and identifying features were removed from the transcripts. I checked transcripts for emerging themes and returned these along with any queries and gaps from the tapes to all the participants for verification. Participants' sex and ranking of the interview e.g. M1, (the first interview with a male patient) gave patients' coding and partners became F6P (partner of female from interview No. 6). Tapes were kept in a locked cupboard by the researcher. Other codes used throughout the thesis are:

- *Italics* – participants' words
- *<u>Underlined italics</u>* – emphasis in speech by participant
- ***Dark italics*** – researcher's words
- ---- - pause in participant's speech
- (---) – edited speech
- Numbers after patient identifiers – line number in that interview
- ** - place identifier

Where names are used, they are pseudonyms.

For the remainder of the chapters an MI will be referred to as a heart attack, as this is the language used by participants.

Potential for harm

Participants recalling major life events can become distressed during interviews. If any participant had become distressed, I would have discontinued the interview, attempted to debrief the patient, and if still concerned contacted the cardiac education nurse or the GP providing the patient consented to this.

One of the ethics committees raised the potential of participants receiving a follow up telephone call from me, only to find the patient had died since discharge from hospital. To overcome this, before making any telephone calls, I contacted the cardiac nurse educators to find out whether any of their patients had died in the previous four weeks. This overcame the issue of confidentiality and ensured no harm to participants

SUMMARY

This qualitative study was designed to find out what patients and partners information needs are following a heart attack. Thematic content analysis was the chosen data analysis method, as it involves semi-structured interviews, which allow the researcher to provide the focus of an interview, while still giving participants the freedom to express their views.

The organisation of data into themes provides a framework for analysing and interpreting data, which can then be audited. Credibility is maintained by this audit trail and constantly returning to the data both in the form of field notes and the transcripts. Ethical clearance is aimed at protecting participants from harm and ensuring confidentiality.

Chapter 4

IT WASN'T TOO DRAMATIC – THE EXPERIENCE OF HAVING A HEART ATTACK

INTRODUCTION

When recalling their experience of a heart attack, patients do it in two stages. They recall the physical symptoms that made them aware something was wrong, and they also retrospectively identify other less significant symptoms, which at the time they did not associate with a heart attack.

The popular concept of a heart attack as a dramatic and sudden event is not supported by the experiences of these patients, but additionally, it does not help them in their efforts to recognise what is happening to them. As a result of patients not being able to identify what is happening, delays of hours to days occur before they seek help from the medical profession. Having a history of angina or a previous heart attack does not impact on the decision to seek help as much as might be expected.

REALISING SOMETHING IS WRONG

It is apparent that heart attacks present in many and varied ways, and no two people will experience exactly the same symptoms. On television, heart attacks are portrayed as dramatic and occurring without warning (Zerwic, 1998). Individuals are shown collapsing and clutching at their chest, signifying severe pain in that area. The reality can be somewhat different.

When asked to recall the experience of a heart attack there was a difference between first timers and those suffering a subsequent heart attack. First timers invariably began with the actual heart attack and the symptom or symptoms that had caused them most distress. They then worked their way back through how they felt and other less severe symptoms or feelings that they had experienced before the acute episode. Participants suffering a second or third heart attack started by recalling the earlier symptoms. Some of the observations highlight the insidious onset for participants experiencing their first heart attack. Participants described every day feelings that retrospectively they recognised as the first sign of a heart attack. Tiredness and exhaustion were the two main problems, common complaints at some time for most people, and certainly not symptoms that would send someone rushing to seek help.

> *I used to get very exhausted after dinner and I was going to lie down* (F8, 66-67).

One woman recalled that five days before her heart attack she:

> *Felt very tired, but apart from that, nothing* (F11, 43).

When asked if he had had a warning, one man said:

> *Nope, nope --- well, I tell a lie, I suppose I had been feeling tired a bit. I always feel tired at the end of the day, and um you know, really one of those things isn't it?* (M7, 19-21).

Tiredness is a common feeling at some time for most people, so recognising it as a warning sign for something more serious is not a likely decision for people to make.

> *Yeah, at my age you have days that you are not as good as you were yesterday. You certainly are never as good as you were at 21! You just write it off as a bad day you know* (M3, 16-18).

> *Before me* (sic) *first heart attack I did notice that pushing me* (sic) *bike out along there I seemed to get a cold feeling in my chest like when you are up the mountain or something like that. Breathing ice-cold air. I didn't put*

> *that down to a heart attack, they said that was probably the start of it* (M4, 100-03).

All participants had a degree of pain and/or other symptoms before the acute event. Invariably this involved them in the process of realising something was wrong. The period involved varied from a few hours to days.

Once patients began to experience pain, they began the process of self-diagnosis to try to decide what was wrong with them. Patients commonly ascribed the pain to indigestion.

> *When I had it, it actually felt like I had indigestion, but I've never had indigestion before. But I had eaten a filled roll and an apple, and it just felt like you know it was, yeah, it was stuck in the pipe* (M7, 10 -12).

> *I had worked a long day, and I came home to watch the football, I didn't feel too good. And my wife made spicy gravy for tea and it upset her and she went to bed early, and I thought that's what it was that upset me you know* (M5, 5-8).

Several participants resorted to everyday remedies to try to control the pain, suggesting that it was within the range of everyday aches and pains, even if the site and type of pain was unfamiliar.

> *Last December, I woke at 3 o'clock in the morning and I got a solid pain here, and I thought what on earth's this? The doctor said, "well what did you do?" I said I took a couple of Panadol and went back to sleep. I didn't know what it was. "Oh" he said, "well you should have rung the doctor"* (F9, 27-30).

> *It was about a quarter to 6 in the morning and I had pains just in here (*indicates inside of arms*) and anyway, I laid in bed for a wee while and um I just got up and made a cup of tea and took a couple of Panadol (--) and anyway, it just didn't get --- well it did ease a wee bit* (F11, 4-8).

The following participant had returned from a fishing trip and was gutting fish, but had to stop.

> *I didn't realise what it was, well I wondered, but I thought I would have a cup of tea for a start, and I sat down and had a cup of tea and that* (F6P, 288-290).

Patients who had not had a previous heart attack were not relating their pain to their heart, but were trying to identify what was wrong based on their previous experiences. Participants with angina or who had previously had a heart attack went through a similar diagnostic process even though they might reasonably have been expected to be aware that the pain could be related to their heart.

> *About ten days before* (the heart attack) *I was just sitting up there and I used my spray and it* (the angina) *went on and on and after the third time it was almost the twenty minutes, the twenty minutes was almost up when it stopped, so I was semi-prepared when it came* (F8, 63-65).

> *I had angina about six years and I have always lived, you know, I knew what I could do and what I couldn't do. I'd always lived within that you know. But then, when it, I'd never had that* (type of pain) *before, and I got told* (afterwards) *it was unstable,* (angina) *because most of the time it was cold that did it you know, like if I walked and it got cold, well ---. (---) Even when it was warm it didn't make any difference, and I knew it* (the pain) *was different at times, but----* (F6, 128-135).

> *I was just sitting here. I pushed the lazy boy thing back and I lay on the bed, no matter what I did I just could not shift it* (the pain). *I thought oh well, I'd better do something about this and I sprayed it* (GTN). *An Australian lady I was in hospital with said she had used it five times a night. I said, well mine was my fourth time and I thought no, I can't go on like this* (F9, 355-358).

The process of recognition was quicker for subsequent heart attacks, but complicated by the fact that the symptoms were not the same as the first time.

> *I had one about the 26th of last month and I finished up in hospital. That was quite a different experience altogether with that one. Then for the first time, I learned what a cold sweat was. I have never experienced that before. I thought I had during the war, but it wasn't that cold. Anyway, I finished up in ICU* (M3, 20-24).

One patient who had had three heart attacks recalled them all and started with the first one. For this one he had no previous warnings and did not feel unwell before it. As he said:

> *It just sort of sneaked up on me* (M4, 39).

With the second heart attack, he developed blurred vision while riding his bicycle and developed chest pain when he arrived home. By dinnertime he had decided that he was having another heart attack.

> *I told* (wife) *that I think I am having another heart attack. I had pain in the chest* (M4, 44-45).

For the third one he again developed blurred vision while sitting in church.

> *I broke out in this cold sweat and I thought my glasses got fogged up. When I wiped them they weren't any better because my vision had gone all sort of foggy, so I went outside and sat down* (M4, 208-211).

Another male patient also related his experience of sweating.

> *It* (the sweat) *was running off me like somebody has the hose going on top of you* (F6P, 309).

In his classic research relating to the patient's perception of his heart attack Cowie (1976) asked the question "why are you in hospital?' (p.87), and found that patients did not begin with the actual experience, but with a retrospective view of what had occurred in the hours or day before the heart attack and then progressed to descriptions of the actual experience. Cowie studied patients following their first heart attack. It is possible that the first timers in this study reversed this process because they were asked what the experience was like for them.

Johnson and Morse (1990) offer a contradictory view of the experience of a heart attack by stating that "heart attacks occur suddenly and with little warning" (p.128), but go on to say that initial symptoms can be mild and are often not recognised as warnings of a heart attack. It appears from the accounts of these participants in this study, that the process is a gradual one, which can take from hours to days to develop, there are warnings and often the actual heart attack is not a dramatic event, but a developing process.

Part of the problem for patients is self-diagnosis and recognising the pain as a heart attack. It became obvious that external sources and beliefs that participants had about heart attacks, including the position and type of pain, influenced this process.

> *Because all the things I had heard about heart attacks, I thought my heart was over here* (indicating the left side of his chest), *but it's in the middle here somewhere and the people that I've heard had heart attacks, they said that their arms ached and it went all up around their necks. Well, I didn't have any of that* (M4, 31-34).

> *I've never felt pain like that, but it never went down my arm, but it was all across* (indicates chest area), *so anyhow, I squirmed around in the chair here and I couldn't find anywhere that would relieve it* (M10. 9-11).

> *But you see you don't really know the pain, you hear different ones don't you (---). It just stayed in here, terrible pain it was, terrible* (indicating the inside of her elbows) (F11, 30-3; 48-49).

While some participants experienced severe pain, it was not that dramatic in onset and there had been previous pain.

> *I woke in the morning with a pain in my chest, the first time I'd ever had a pain* (in the chest) *and after breakfast it disappeared. But that night, it was a Saturday night and I was sitting here, and all of a sudden I just got this pain in my chest. It was the worst pain I've ever had* (M10, 4-7).

> *With my first heart attack in 1997, I sort of thought I can't be having a heart attack, no I'm not, but I had pain across the chest and walked around like that for two days before I arrived up at the hospital* (M4, 23-25).

One patient was confused because he experienced pain in his back, not dissimilar to pain from an existing back injury.

> *I had the pain, but I get a lot of pain in my back, and even in my legs from my back, so you know ---* (F6P, 311).

The recognition that something abnormal is occurring is prompted by one or more symptoms. The diagnostic process itself is described as occurring from the first time that the illness causes a discontinuity in normal life (Benner & Wrubel, 1989). The process of making a diagnosis is described as the "recognition and labelling" stage (Alonzo & Reynolds, 1997). Symptoms are lived experiences and as such relate to a person's philosophy, experiences and social transactions (Benner & Wrubel, 1989). The process of self-diagnosis for patients starts with one or more symptoms and links into what they know and could reasonably expect, such as indigestion, fatigue or an unexplained ache or pain which will settle with over the counter analgesics or a cup of tea.

The initial reaction to symptoms is described as attempts by patients to normalise the situation by Johnson and Morse (1990) and Cowie (1976) who conducted research with people following their first heart attack. Johnson and Morse link this to a patient trying to maintain control of the situation by "defending oneself" (p. 128). Whilst there may be an element of this defending in participants undergoing a second or third heart attack, it is more difficult to reconcile with first timers.

Another theory is that patients and clinicians have "frames of experience" (Jairath, 1999, p.284), which they bring to the diagnostic process. While the clinician's frame is based on making a diagnosis, the patient's focus is more likely to link to the psychological effects of what is happening. Jairath feels that there is a danger of patients modifying descriptions of the pain sensations to match the clinician's focus. She also puts forward the patient's frame of experience for failing to identify, until after the event, the fatigue that many patients retrospectively recalled. She feels there is an urgent need to improve communication between patients and clinicians in the experience of a heart attack.

If, as Benner and Wrubel (1989) state, symptoms relate to previous experiences, it is not surprising that self-diagnosis does not include a heart attack. As interviews with these people will always be retrospective to the experience of a heart attack, it is probably a presumption to describe them as normalising symptoms. They are simply diagnosing within their own framework of knowledge and experience. Frameworks relating to illness and disease can be shaped by sources such as friends, media, books and health care providers (Meischke, Yasui, Kuniyuki, Bower, Andersen & Urban, 1999) and will include expected symptoms based on experience, hearsay, science and drama, depending on the source.

Authors who describe this process of self-diagnosis of indigestion and other everyday ailments as denial of a heart attack (Benson, Arthur & Rideout, 1997; Lowery et al., 1992; White Robinson, 1999), may be reading too much into the situation or, with their emphasis on diagnosis (Jairath, 1999), over simplifying the process. As Scherck (1992) says, an alternative view is that rather than denial at this stage, the process of "recognising the onset of an acute myocardial infarction is maybe a difficult task complicated by the variability of symptoms present" (p.331) and Cowie (1976) concludes that a heart attack is "rarely immediately recognisable as such to those experiencing it" (p.94). He also acknowledges that patients frequently make the diagnosis "by default" (p.89).

The fact that the heart attack is not a dramatic event and therefore not immediately recognisable as a heart attack impacts on the time people take to seek medical help. In this study, the period varied from a few hours to days. Seeking medical help occurred when symptoms became too severe to tolerate and /or had not responded to self-medication.

DECIDING TO SEEK HELP

One woman, who is quoted earlier as trying Panadol and tea at a quarter to six to relieve the pain, continued her story.

> *I got up again about a quarter to seven and went and got my paper and still had it* (the pain) *(---). Time went on and I had a little breakfast, I didn't eat much, and then I had another cup of tea and I thought oh, I will go to the medical centre* (F11, 8-12).

The man who went to bed after his wife's spicy gravy but had felt tired all day, woke his wife at about 10.00 p.m. to call the ambulance. He subsequently suffered a cardiac arrest and was resuscitated at home by the ambulance crew. A slightly longer delay, or deciding on another method of transport to seek help may have resulted in a very different outcome.

It might be assumed that the constant nature and severity of pain would cause patients to seek help earlier, but this was not the case.

> *So eventually we went to bed, but I didn't go to sleep, I only dozed. Then about 4.00 in the morning it was still there and I couldn't find any position that would relieve the pain* (---) *so I thought it must be a heart attack* (M10, 12-14).

At this stage he decided to call an ambulance. The unrelieved severity of the pain finally, but not immediately, resulted in the recognition that help was needed. Even then he had a debate with himself as to whether to call an ambulance or a taxi, and decided on an ambulance, but only because he thought it would get him priority treatment. It was a Saturday night and he anticipated that Accident and Emergency would be full of "*all the yahoos that get drunk*" (M10, 20). These last two participants also raise the issue of <u>how</u> to seek help, which is discussed further on.

Histories of angina did not cause patients to seek help earlier. Delays occurred from a few hours to, in one extreme case, days. Even then the next patient sought help from her GP not the hospital.

> *I started to get sort of uncontrollable angina and decided - it had started on the Sunday night - decided on the Wednesday morning I think it was, wasn't it* (to partner) *that we must come in, so we came in and went to the doctors* (F6, 9-11).

For the majority of participants the decision to seek help and the process involved was not dramatic.

> *There was no drama* (M3, 9).

> *He came in and said he wasn't very well; we just sort of took everything in our stride* (M3P, 9).

> *I woke her up and said "you had better ring the ambulance; I'm having a heart attack"* (M5, 10-11).

Most partners were also prepared and some had identified that all was not well.

> *It wasn't too dramatic, (---) we sort of had been living you know, like that, but sometimes she's not very well and something could happen. So ---. She took things very calmly, it wasn't too bad and um just one of those things* (F8P, 3-8).

> *I wasn't particularly surprised. I just couldn't put my finger on it, he wasn't quite right* (M4P, 21-22).

> *The angina, and the way it was developing and becoming more frequent and more severe and the puffer was not working. I was well, aware that this sort of thing could happen* (M3P, 6-8).

> *She* (her partner) *rung up the nurse and she, you know, explained what had happened and she said, "ring the ambulance" (---). Of course they moved very quickly, they are very good aren't they?* (F8, 73-75).

It appears that the reactions of medical personnel are the first introduction of drama or awareness of the seriousness of the situation.

> *I heard them mention the ICU; I thought gee whiz, I must be pretty serious* (M10, 29-30).

> *Anyway, I finished up in ICU* (M3, 24).

One woman who drove herself to her GP said:

> *I was a bit breathless when I got down to the doctors. I was alright when I left, but when I got out of my car and walked in I felt a wee bit wobbly and anyway I just said to the receptionist "I'm Joan of **" and she said "Joan you don't look very well". I said, "I feel terrible"* (F11, 505-508).

One of the men who was at work described what happened:

> *I was actually out on site. I found my supervisor and said I didn't feel too good (---). They found a nurse, the industrial nurse, she took one look at me and knew what I was having and then cut the shirt open ready to zap me because they thought I was going to go* (M7, 24-29).

Out of the 12 experiences of a heart attack, (including the partner who had also had one), only one person sought immediate help and this was M7 who was 10-30 years younger than the other participants. He was at work. Had he been at home it is likely that he too would have delayed seeking help, particularly as he had already self-diagnosed indigestion.

Some of the partners wanted to seek help before the patients did, but were over-ruled until the patient had completed the self-diagnostic process and arrived at a conclusion that something was seriously wrong.

> *Several times previously when he had had an angina attack and I suggested that we should perhaps ring the ambulance and he would sort of say, "I'm alright, I'm alright" (---). But this time he looked, you know, he admitted that he wasn't as well and all that sort of thing so it was – there wasn't any hesitation about calling the ambulance* (M3P, 13-18).

> *I rather thought he might be going through it again; he had no repercussions from the first one. Just before the second one I caught him a couple of times having a go at the nitro-glyceryl spray at rest, which concerned me a bit, so I thought oh well, perhaps there's going to be another little thing* (M4P, 16-19).

Her description of "another little thing" also downplays the seriousness of the situation. Relatives of patients who had not noticed major changes suggesting a heart attack were the ones taken by surprise.

> *The first one, I was a bit stunned because I really didn't think he was sick enough* (M4P, 3-4).

The wife of the youngest patient whose heart attack was totally unexpected related how she was:

> *Just shocked, really shocked* (M7P, 9).

At some stage patients recognise that the problem is not an everyday one. Cowie (1976) found that the move into recognition that the incident was serious was an increase in the severity of pain, or in some cases sudden severe onset of symptoms that could not be normalised according to previous experience. The patients in this study supported this. The jump from identifying a symptom as serious instead of commonplace appears to relate to it reaching a level where the patient is constantly aware of it. A defining moment is when the symptoms begin to impinge on their whole existence and affect their ability to perform normal tasks and carry on with life. These are described as triggers by Scambler (1986), and are usually the prompts needed to seek help.

Having a previous history of a heart attack or angina, did to some extent prepare patients and relatives for a heart attack, even when it was the first one. For most people a history of angina, particularly if recent attacks were becoming more severe, also provided warnings, although interestingly some of them ignored the advice to seek further help if GTN did not relieve their pain. This is an area where more education appears to be needed so that people are made aware of the importance of seeking medical help if GTN does not relieve their pain.

Failing to seek help as soon as symptoms of a heart attack arise can have a major impact on mortality and morbidity (Alonzo & Reynolds, 1997). Receiving thromboembolytic treatment within one hour of onset greatly reduces mortality and the size of infarct damage (Dracup & Moser, 1997).

Studies in the last 2 decades show median delays in seeking help of between 1.5-6.5 hours (Dracup & Moser, 1997). These authors also report that between 25-50% wait longer than 6 hours before seeking help, and some patients wait even longer than this, sometimes in excess of 24 hours. Significantly longer delays occurred where patients had intermittent rather than continuous symptoms (Dracup & Moser).

As was shown in this study, the decision to seek help is most often left to patients even when the spouse recognises something is wrong (Cowie, 1976). Apart from deciding when to seek help, patients also have to decide how to seek help.

HOW TO SEEK HELP

Although patients with a history of angina are advised to dial for an ambulance if symptoms have persisted more than 20 minutes and are unrelieved by the use of GTN spray, it seems that this advice is often not heeded. This appears to be an educational issue where information to patients could be improved and might help in achieving reduced rates of an MI occurring. Interestingly, more patients without a history of angina opted for an ambulance than those with it. Figure 4 shows how the participants in this study chose to seek help.

Patient	Sex	Angina	Ambulance	Self Drive	Driven by partner	Medical Centre or G.P.	A & E
2	F	✓	✓	-	-	-	✓
3	M	✓	-	-	✓	-	✓
4	M	✓	-	-	✓	-	✓
5	M	-	✓	-	-	-	✓
6	F	✓	-	-	✓	✓	-
7	M	-	✓	-	-	-	✓
8	F	✓	-	-	✓	-	✓
9	F	✓	✓	-	-	-	✓
10	M	-	✓	-	-	-	✓
11	F	✓	-	✓	-	✓	-
6P	M	-	✓	-	-	-	✓

Fig. 4. Selected ways to access and seek help. NB.Data not available for M1

Figure 4 also shows that seven patients had a history of angina. The two men with angina had only had it since their first MI, whereas the women all had angina before their first MI. Of concern is one woman who drove herself, because her self-diagnosis did not acknowledge that she was having an MI.

> *I wouldn't have done it if I thought it was a heart attack.*
> ***Because you drove there did you?***
> *Yes. But I honestly wouldn't have because they would have thought "what a silly thing to do"* (F11, 16-19).

This woman was then sent on to the hospital in an ambulance by her GP. It was interesting to note that her concern was for what the medical staff thought of her driving rather than the risk to herself or others of the action.

Although not mentioned by me during the interviews, there is evidence that cost can be a deciding factor in whether or not people choose to take an ambulance; three patients mentioned the cost of using an ambulance. One in particular, whose decision was based on the fact that she lived on her own and it was the only way to summon help late at night, was obviously very upset.

> *So it cost me $45.00 for an ambulance. Then the emergency doctor sent me a bill for $75.00. My daughter went crook, she said "she's got her community card" and so they knocked it down to $16.00* (F9, 16-19).

Given that this patient identified financial worries as a cause of her heart attack, paying to receive emergency care would do little to reduce this as a cause of her stress, and obviously nothing was sorted out until her daughter intervened. Another couple opted for the wife to drive her husband to hospital, although she stated that if necessary, she would use her savings and order an ambulance if it happened again.

Sarafino (1990) reports on a research study that found the cost of treatment was one of the factors influencing the decision to delay seeking help. He was relating this to total care costs in America, which is different to New Zealand, but it would be interesting to look at the impact these emergency care costs have on help seeking decisions made by patients in New Zealand, particularly in relation to heart attacks where prompt treatment can have such an impact on outcomes. It was obviously an issue for three of the participants in this study, but apart from Sarafino, I could find no mention of this in other studies. Health authorities might well find it cheaper to fund ambulances for these patients than pay out the cost of health care related to morbidity.

HEART ATTACKS – WHAT IS A COMMON SYMPTOM?

The results in this study showed that all patients had a variety of symptoms and types of pain. Following a research project involving 414 men and women participants, Zerwic (1998) identified 16 different presenting symptoms and 16 different sites for pain, varying from different regions of the chest, abdomen, legs, arms and back, to the throat, jaw and teeth. Additionally 13 different types of pain were identified, tightness and pressure both rating higher than crushing, which is often perceived to be the most common type of pain in a heart attack. Zerwic (p.79) concludes, "There is not a standard set of symptoms experienced by all patients experiencing a myocardial infarction".

As a means of reducing morbidity and mortality from heart attacks, it is suggested that the public are educated to respond to and recognise signs and symptoms of a heart attack (Alonzo & Reynolds, 1997). Given the range of symptoms and the insidious nature of onset, this is not a realistic expectation. What might be more constructive is education to at risk patients, particularly those with angina, of the signs and symptoms that may indicate that they are having a heart attack and the need to seek medical help.

The internationally recognised Framingham Study (Kannel & Feinleib, 1972) identifies that angina which has increased in severity or become unstable is often a warning of the heart attack to follow. This was the case with the admittedly small numbers of patients with angina in this study. Education on the implications of changes in angina and why they are recommended to seek help when their coronary vasodilators do not work may improve outcomes for this group.

SUMMARY

Recognition of a heart attack is a complex process, not least because symptoms and types and site of pain vary from person to person. Nor do they match the media portrayal of a sudden dramatic event. Some previous writers who have described these people as normalising a heart attack have focused on the diagnostic process. While patients do self diagnose, it is within their own frame of reference, which causes them to find everyday reasons for their symptoms.

It is not until pain becomes severe or continuous, and everyday remedies have failed to control the symptoms that people seek help, and it is often this first contact with medical staff that introduces any drama or knowledge that something is seriously wrong. Whilst seeking help earlier is likely to reduce mortality and morbidity figures, it is difficult to suggest ways to educate the public of the signs and symptoms which should send them to seek help, given the wide variety and innocuous nature of the early signs and symptoms.

Chapter 5

THEY DIDN'T EVEN THINK IT WAS A HEART ATTACK – THE EXPERIENCE FOR WOMEN.

INTRODUCTION

In this study, unlike the men, all the women had a history of angina before their first heart attack. This, coupled with the possibility that doctors diagnose heart attacks on expected symptoms that the women did not experience, led to delays in the diagnostic process for them. An emerging area of concern in relation to nursing is the apparent lack of empathy by nursing staff for these patients, resulting in physical and psychological distress as well as inadequate treatment for the women.

KNOWING SOMETHING IS WRONG

Before undertaking this study, I had been aware from teaching anatomy and physiology to nursing students that male and female patients experiencing a heart attack can present with different symptoms. As this difference did not form part of the research question, no literature review was done on this topic. As the five female participants described their experiences, it became increasingly clear that the diagnostic process for women was less clear cut than for men, and that this caused unnecessary suffering and worry to these patients. Additionally, all five women identified that what they wanted to know was why they had not been correctly diagnosed as having a heart attack and why they were not given pain relief when they needed it.

In this study, the men all complained of chest pain, discomfort or heaviness and /or arm pain, and sought help when this was interfering with their life and not resolving. They were all transferred straight to ICU or CCU. The women, with their histories of angina (see Fig. 4), all tried their GTN sprays, and in the one case Panadol as well, and sought help when this failed to resolve the problem. Only one woman was sent to CCU.

The two women who went to their GPs were sent straight on to hospital in ambulances, suggesting that the GPs suspected a heart attack, but hospital staff seemed unable or unwilling to make the diagnosis of a heart attack or, in one case, even angina.

> *The doctor that first interviewed me (---) she said "I don't think it's angina" and I felt like saying "it is". He* (another doctor) *came in and he said "I don't think it's angina, but we will admit you overnight"* (F8, 83-85).

This also demonstrated how the patient's knowledge of their condition could provide a guide to what is wrong if only medical staff would listen to them. Another example of this was the following patient who stated:

> *They kept on saying that "we know the difference"* (between the pain of angina and a heart attack). *You know the difference yourself* (F6, 280-281).

And later:

> *I don't know whether they – I had the feeling they just thought I was having the angina or something and not a heart attack* (F6, 274-275).

As one woman put it when describing the difference between the pain of angina and heart attack:

> *You get such different pains* (F11, 39).

One problem was the apparent inability of staff to listen to what the women were saying about their pain.

TRYING TO GET PAIN RELIEF

One participant not only had unresolved pain, but also was able to compare her experience with that of her husband when he had his heart attack.

> *I was using the spray all the time to try and help myself and that. In the end, I don't know, about 4 o'clock in the morning or something they gave me a couple of Panadol* (F6, 36-38).

Then later:

> *Yeah, and his was --- they were banging morphine into him left, right and centre. They kept saying to him "if you're having pain, you know, we've got to give you more." And I was just the opposite. I was trying to get them to give me something and they wouldn't give me anything. I don't know why* (F6, 44-47).

She subsequently underwent coronary by-pass surgery. Her experience also shows how medical diagnosis affects what type of analgesia patients receive. Her husband related how an additional medical problem confused the diagnostic process. She had been experiencing an increase in her pain after meals and had a history of ulcers. He stated to his wife:

> *"You've got ulcers" and I think the doctor at the time was thinking it was more a stomach related problem* (F6P, 274-276).

The severity of pain is linked to stress and emotional disturbance (Miklaucich, 1998). Giving morphine intravenously in A&E is part of the standard medical treatment for patients experiencing a heart attack; this is both to relieve their pain and their stress, which in turn reduces the workload for the heart. In this study, only one woman received morphine and that was after admission to ICU, not in the A&E.

> *They were trying my spray, but that did no good and in the finish, they got me morphine (----). They actually took me down to ICU (---) and then you know they gave me a bit of morphine, it did help me, but you see they didn't even think it was a heart attack* (F11, 56-65).

Medical management of pain relief for the remaining four female participants varied from continuing with the GTN to sleeping tablets or Panadol, although it is not clear whether there was stronger analgesia prescribed which could have been used. Considering the instructions given to patients relating to the boundaries of using GTN, and that they had been using it beyond these before admission, it is difficult to understand why morphine was not given.

One woman who was given sleeping tablets woke with the pain the next morning, although she said it was not severe.

> *I had the pain the next morning - a little bit,*
> ***And what did they give you for that?***
> *Just a spray. There was a young nurse and he said "oh well, give it a go and I will be back" and he came back in five minutes and said, "try it again." Then he came back and said, "how is it?" I said, "oh, it's just about gone"* (F9, 261-265).

Another woman described how she had pain but was not given analgesics because *"It really wasn't that bad"* (F8, 125).

I did not seek this information on pain, or gender differences; it emerged as participants recounted their experience of a heart attack. Significantly, none of the men mentioned pain after admission to hospital, and the assumption is that as they were all transferred to ICU or CCU, they received the accepted regime for heart attack patients, which includes intravenous morphine and monitoring of pain.

A disturbing finding was the apparently deaf ears that greeted the women's complaints of pain. Two issues arise here; the first one being the role of advocacy for patients by nurses and the second the medical framework referred to in Chapter 4 that shapes clinician's diagnostic decisions. Nursing should focus on the patient and family and their social and psychological needs (Kraegel & Kachoyeanos, 1989). These authors describe how to heal the body, patients need to be relieved of any concerns that impede physical recovery; and both pain and distress could be placed in this bracket.

Within their own working environment, nurses have choices they can make which may involve supporting the more mechanistic, medical model of caring, or embrace the best interests of patients by using patient empowerment or autonomy models (Brown, Kitson & McKnight, 1992). Nurses working within an empowerment or autonomy model would be more likely to take notice of what patients describe as their problems rather than relying on the medical diagnostic process. Examples of how nurses can reach a correct diagnosis in situations where medical staff have failed to do so are included in Benner, Tanner and Chesla (1996), and Kraegel and Kachoyeanos (1989).

RECEIVING A DIAGNOSIS

For women, the final diagnosis often depended on the return of cardiac enzyme blood results.

> *One of the doctors came around - they said they didn't think I had a heart attack. I thought well, that's alright then, (---) of course the day before they had taken different test, ECGs and then they had taken this blood test --- and five minutes later the doctor came back and she said "I'm sorry but you've had a heart attack. You will have to stay in bed and you are not allowed to get up now"* (F8, 85-90).

Her partner, who thought there was nothing seriously wrong, related how the patient had already been allowed to mobilise since her admission, but subsequently the situation appeared to become more serious:

> *The next morning they said it was a slight heart attack, so it gradually became more* (F8P, 22-23).

The following woman was admitted on Saturday night.

> *The Sunday they told me that it was a heart attack, so I presume more tests had come back and showed up, because my daughter and son-in – law were flying* (0verseas) *and they told her "no, it wasn't a heart attack"* (F11, 117-119).

This information had been given to the daughter-in-law on the Saturday night before her flight, and she then continued on her holiday. This obviously distressed the patient who referred to it three times during her interview.

> *And then I was talking to the nurse up at Intensive Care --- my son and my daughter and um, the nurse said, "do you feel happier going away now that Mum hasn't had a heart attack?" And she said* (the daughter) *"oh yes"* (F11, 342-344).

And a woman who came in on the Tuesday saw the doctors on the Wednesday.

> *Well, they sort of hummed and ha'ed, and didn't know whether I had had one or not. They took blood all the time, and that, and they reckoned that it* (the cardiac enzymes) *was up in my blood tests and they sort of decided* ---- (F6, 313-315).

Another participant was sent to the hospital by her GP with a suspected heart attack, but discharged without being admitted. Two weeks later she was re-admitted as an emergency. One is left wondering whether her emergency admission could have been prevented with different diagnosis and treatment on the first admission.

IMPLICATIONS FOR WOMEN

In this study, the process of correctly diagnosing women was far from straightforward, suggesting that the clinician's framework of experience was not accommodating the women's symptoms. Part of the problem may be that both patients and clinicians still largely see heart disease as a man's disease (Halm & Penque, 1999). The framework of 'normal' symptoms for a diagnosis of heart attack was built on studies of predominantly male participants (Johanssen, et al., 1983). As women often present with a different set of symptoms to men (Benson, et al., 1997: Travis, Gressley & Phillippi, 1993), they fall outside this framework. In this study all five female patients had a history of angina, compared to two men, but more importantly women had angina before they had had a heart attack, whereas the men only experienced angina after a first heart attack. It is possible that existing literature and preconceptions relating to women and heart disease compound the problems for women of doctors making the correct diagnosis.

The Framingham study (Kannel & Feinleib, 1972) is one of the most comprehensive on gender differences, and the most significant finding was that more women than men with IHD presented with angina, 61.5% against 36.8% however, the risk of women with angina presenting with a heart attack was less than that of a man. A more recent study reports that women often have atypical angina, which does not progress into acute problems (Travis et al., 1993). The main presenting symptoms for women were changes in the severity or type of angina, and as was discussed in Chapter 4, these can be the impending signs of a heart attack (Kannel & Feinleib, 1972).

It is not clear whether all the women had an ECG, but even if they did, women tend to have fewer diagnostic changes on ECG than men do (Jensen & King, 1997). This relates to several differences in the female cardiovascular anatomy and physiology that can impact on the diagnostic process (Jensen & King). Some factors, which affect how medical staff arrive at a diagnosis, include recognition of a disease by its most commonly encountered symptoms (Benner & Wrubel, 1989). They describe how this process is selective and has a capacity for bias because "symptoms inconsistent with the hypothesized diagnosis are overlooked or discounted" (p.201). An example of this was given by one woman who said:

> *Because everybody,* (clinical staff) *always says to me you know, "were you short of breath," "are you short of breath?" And I was never short of breath. I think that's why a lot of them thought you know* --- (that she had not had a heart attack) (F6, 303-305).

It would appear that some clinicians might need to change their framework for diagnosing a heart attack, especially where women are concerned. More importantly nurses need to ensure that they are listening to and acting for their patients. This is in line with Price (1996), cited in the literature review, who calls for nurses to empathise with the experience of patients. Additionally, White Robinson (1999) suggests cardiac educators are the way to provide individualised care to patients. While she was referring mainly to rehabilitation, it may be possible for specialist cardiac nurses to be involved more in the admission and diagnostic process.

An additional problem for women is the evidence that suggests that they delay seeking help for even longer than men (Penque et al., 1998). The authors offer as a possible explanation for this the fact that "women in general do not experience signs and symptoms in the same manner as do men" (p.176), which was supported in this study. Thus women have a double problem in terms of receiving the correct treatment for their heart attack within the optimum time range that of failing to seek help early enough, and then failing to have their heart attack correctly diagnosed.

SUMMARY

Listening to the female participants, it became obvious that the diagnostic process for women resulted in a different experience for them than for the men. Unlike the men, all the women had histories of angina before their first heart attack, and this along with differing symptoms, resulted in failure by medical staff to correctly diagnose a heart attack until 12 or more hours after admission. This has major implications for the treatment outcomes for women, especially when linked to literature reporting that women generally present later than men anyway.

Apart from efforts to increase awareness in medical staff of differences in how men and women may present, there is a need for nurses to examine their own practice in relation to these patients. Allowing patients to suffer pain and uncertainty when both could be more appropriately addressed must be of concern to nurses working in these areas.

Chapter 6

TELL ME WHAT MY PARTICULAR PROBLEMS ARE – THE SEARCH FOR RELEVANT INFORMATION

INTRODUCTION

Formal education for patients following a heart attack takes place in three phases, two of which are covered by this study. Phase 1 occurs in hospital and Phase 2 following discharge. While a wealth of information is provided to patients and partners, there is evidence that much of it is ignored, misunderstood or not retained and patients and partners are left lacking the information they really want relating to their own experiences. Where staff do provide information relevant to the individuals, it is greatly appreciated, and likely to improve their ability to cope after a heart attack.

FAILING TO MEET INDIVIDUAL INFORMATION NEEDS

There were four main stages in the information process that emerged from the interviews with the participants. These were while in hospital, which encompasses Phase 1 of the cardiac education process; during discharge; immediately post-discharge and once Phase 2 cardiac education classes started. Some participants did not experience the latter, as they did not attend the classes.

Phase 1 Education

Phase 1 education takes place while the patient is in hospital, and in the words of the NHF (1997, p.4), should begin:

> As soon as the patient is symptom-free and able to start discussing their condition. The programme should help patients begin to develop an understanding of heart disease, assist in physical and psychological

recovery, provide information about risk factors and their modification, and increase patient's sense of control.

A priority that emerged for patients and partners, was finding out exactly what had happened, but there was evidence that this information was not absorbed during the acute early hospitalisation period. Two men told me what they understood:

> *Just that I was having a heart attack, that's about all really I think ---*
> ***Did they explain more about what was happening to you?***
> *Not really, no --- not a lot, er --- not that I can remember anyway* (M7, 32-35).

> *They said, "you are having a heart attack," whatever they call it infar-- something (---). They just said I was having a heart attack and "what was the degree of pain I had" and all that sort of stuff* (M4, 8-9 &15-17).

This also demonstrates how medical terminology can confuse patients, and means nothing to them. It is important for staff to communicate in easily understood language.

Some of the patients admitted to ICU said that they did not know what days or how long they were in there, and one of the contributing factors is likely to be related to the effects of morphine if this was the analgesic being given. As one participant described his memories of ICU:

> *A bit befuddled, because you know I was away with the fairies at times* (F11, 114).

In a study of ICU patients, Russel (1999) found that some patients remembered everything about their stay, while others had distorted and/or few memories about it. Relatives too can be in a shocked state following their partner's admission for a heart attack and this will affect how they interpret information (Thompson & Cordle, 1988). Starting the information process in ICU, unless specifically requested by patients, is probably not a useful process.

Of more concern is that when patients went home eight participants indicated they still did not know what was wrong with their own hearts. They acknowledged that they had received information, but it had not provided what they needed to know. Example of the gaps in their knowledge included:

> *I don't really know what's exactly happened to my heart. (---) I've got these different things and I also belong to the Heart Foundation, (--) and they send you bits and pieces, but I didn't know a lot, ---I don't really know what my trouble is* (F8, 250-254).
>
> *Yes, I learned quite a bit about my heart. How it worked and all the rest of it, where it is and what happens* (long pause), *so yes, I don't know what sort of damage has been done to my ticker, moderately severe they said* (M4, 60-62).

Information on how the heart works and what a heart attack is was delivered by three methods. Videos and reading material were the standard deliveries and information directly by staff the third alternative.

The importance of using different methods of delivering the information was illustrated by the preferences of participants. Some patients benefited from videos, although the ones which they remembered related to stress and the recovery process, the anatomy and physiology ones were not see as useful, except where patients were going on to have an angiogram, and what they saw was specific to that process. As one patient put it:

> *I have always found videos to be, the fact that they are graphic, you don't miss anything, --- but people will watch a video --- it does not mean that*

> *they absorb it. I think it could be done so much better. I think if you have got videos not as general as we tend to have (------) I would certainly like to see a range of videos for this person who just has angina, or this person who has actually had a heart attack* (M1, 167-177).

One patient identified that he only remembered one video, which is hardly surprising, but it was obviously one that met his own need. I had asked him which information he had found most useful and his reply was:

> *The video, the first one I saw. It was about a bloke who had a heart attack and how he was recovering, sort of. He must have had a real bad one because he was six months getting over it. How his family coped and all that* (long pause) *I think a lot of these things it's worse for people looking on than the person who is right in the middle of it* (M4, 195-200).

He did not, however, appreciate the efforts of staff to make him watch all the videos in the selection.

> *They thrust videos at me when I was on the ward --- thrust videos on me. I wanted to watch the rugby on the TV set and they jacked up a TV set for us to look ---"have you seen this video? This is very good; you had better have a look"* (M4, 186 -188).

This illustrates the need to individualise the education being delivered. Sometimes patients and partners have already seen videos, as with the woman whose partner had his MI the year before.

> *You know a lot of the videos and that, if we were asked to watch them you know, we said "oh, we've already seen them." Some of them we watched again* (F6, 232-234).

Another participant said she had not seen any videos, but when she returned her interview summary, she said that she had seen a video on CPR (Cardio-pulmonary resuscitation). If this recollection is correct it is difficult to see its relevance to a patient rather it has the potential to be alarming, although it obviously did not have a major impact on this patient.

Reading material is in the form of standard leaflets dealing briefly with the anatomy and physiology of the heart and other related issues. There are also books available that are loaned to patients. What appears to be lacking is a process of checking whether patients understand what they are reading, and whether it means anything to them.

> *They gave me a book to read. This chap said "well I'm bringing you a book to read" and he says "I'm going to test you on it in half an hour." I said "well, is that right?" Well, I had it for about three days and then somebody else needed it. Just tells you what a heart attack is and what it does* (F9, 91-95).

A couple of patients did acknowledge that the advantage of reading material was being able to return to it.

> *I think reading is the best, because you know if you don't take it all in the first day, you can always read it again can't you?* (M7, 86-87).

However, even this was not foolproof:

> *I sort of read a certain amount, but the trouble is I read it and it goes from me* (F8P, 48-50).

This inability to absorb information is not uncommon in a stressful situation. There needs to be a balance in providing the right amount of relevant information in written form. One patient told me:

> *The day I came out of hospital I was in the finish, I just switched off. You sat there nodding your head and you screwed it up and threw it all in the rubbish* (M5, 91-92).

As well as written information the staff still provide much information verbally. One problem seems to be whether people are told too much and can't remember it all, or whether they are not told enough, or have this concept because they cannot remember what they have been told. The differences in how participants benefited or failed to benefit from the information provided indicate that the present system fails to meet all information needs. The following two sub-themes address these two areas.

I DON'T THINK I WAS TOLD MUCH

Apart from the examples included earlier in this chapter, which related mainly to patients, there was evidence that partners rely most heavily on staff as a source of information. All the partners identified that they only received information when they were with their partners or they sought it out. A result of this could be that partners who do not seek information may have to cope without it. As one woman said:

> *---if I wanted to know, I just went and found somebody and asked, but not everybody would do that and I think that if you have somebody who was a bit diffident and who hadn't had a lot of experience working in hospitals and in medical situations and who treated doctors as God, um they probably would come away with as little knowledge as they went in with, except what the spouse gave them second-hand, or what they learnt from the leaflets* (M4P, 133-138).

One woman related how:

> *They did explain to you everything, but I can't remember* (M7P, 23).

In fact the only thing she did remember was when:

> *They told me about the drugs they were going to given him that could cause strokes and that ---* (M7P, 16-17).

This was hardly the most reassuring thing to remember and yet the one piece of information which had stayed with her. Another partner with difficulties related how:

> *I wasn't speaking to anyone; I just got it* (the information) *from Elizabeth* (F8P, 30).

This was the same partner who identified that she could not remember what she had read. Later she said:

> *I don't think I was told much; it was just from her* (F8P, 33-34).

This participant admitted that talking to me had been "quite good" (F8P, 55). Four participants asked me questions that showed their need for more specific information, another example being a woman who was waiting to hear about her stress test because she had had an:

> *Acute --- oh, you would have it down wouldn't you?*
> ***Myocardial infarction***
> *Yes, something like that* (F11, 360-363)

And then:

> *Is that a heart attack, what type?* (F11, 365).

She then went to get a letter from the hospital and I had to explain what the treadmill test was and that they would send an appointment, and what it was for.

Her confusion had been obvious earlier in the interview:

> *You know they explained things and did all me* (sic) *blood tests and things --- I'm not up with --- you know, a lot of people are up with the medical* (jargon) *aren't they, but I'm sort of not. At times I think I should find out more* (F11, 127-130).

Interestingly, despite her confusion, and not seeming to realise she had had a heart attack, she then went on to say:

> *They explain things to you very well, I mean they gave me a little pamphlet and put a little bit down here what the damage was to my heart* --- (F11, 373-374).

Additionally, both F11 and M4 as previously quoted were confused by the use of the word infarct by staff and did not know what it meant. A recurring theme was how the information given can fail to leave the patient or partner with any understanding of what has happened to them or their partner.

Three patients mentioned problems with communicating with foreign doctors, but the overall impression was that medical staff were more approachable and forthcoming than in the past, as indeed were other health professionals. Referring to a dietitian, one participant said:

> *She was --- they are much more, how should I put it --- I don't mean professional, much more human than they used to be and I think the doctors are exactly the same* (M3, 168-170).

With regard to doctors:

> *Yes, I felt I could ask anything, yes. I think on the whole the medical profession today is much more forthcoming with the information* (M3P, 27-28).

And nurses:

> *I certainly found nursing staff to be – um very helpful, and anxious to try and answer your questions* (M1, 126-127).

This patient identified nursing staff as his best source of information, finding two nurses to be "*absolutely first class*" (M1, 111). Of one he said:

> *I had to go to ** because of arrhythmia problems (----) When I went to **, um this nurse went out of her way, because I wanted to find out the – as I say – the electrical patterns of my heart, I thought it was most interesting, and she went straight home, because she was going off her shift, and went in her own time and copied this book. She went home, and she had this particular book, as she said it was most appropriate and copied the pages (--) I was very impressed* (M1, 113-125).

A doctor at one of the centres was constantly praised and some patients mentioned his efforts to provide individual information, usually by taking the time to draw diagrams.

> *Oh yes, Dr X was very good; he drew a diagram and showed you exactly what was happening* (F2, 6-8).

In the literature review, Chan (1990) and Duryee (1992) both reported that the need to know how a heart attack happens was not highly rated by patients. Duryee, who was reviewing the literature on the effectiveness of inpatient education, suggests that anatomy and physiology should not be covered during this period, and it appears that much of the anatomy and physiology is not understood or absorbed. Patients and partners do want some information, but specifically relating to what damage has been done to their heart, or their partner's heart, not general information on heart attacks.

In relation to partners, seeking information is a form of coping and the period in hospital was identified "as a time when spouses were constantly seeking help in the form of meaningful information about the patients status and disease" (Dickerson, 1998, p.14). In her qualitative research, she identified how some spouses were able to seek information while others had problems communicating their needs, and that the patient's needs were put before those of the spouse. While the patient is the main concern for hospital staff, the partner plays a pivotal role in the recovery process (Beach et al., 1992; Dickerson) and needs to be kept informed, with the consent of the partner.

The experiences of the partners in this study support the findings from the literature review of Coyne and Smith (1991) that they are not always treated as active partners with a role in the recovery process and of Thompson and Cordle (1988), who reported that 63% of partners did not have enough opportunity to ask about the heart attack. This impacts on how both patients and partners adjust following a heart attack. The other subject covered in Phase1 is risk factors and in fact this forms the main focus of the information provided.

BEING INUNDATED WITH INFORMATION

In Phase 1, the amount of information provided appears to defeat the purpose of informing patients and partners; it results in overload and there is also the confusion from the number of different people seeing patients.

> *I was actually inundated with information; I really was, even to the extent where I had the pharmacist come and explain in <u>great</u> detail the drugs, the performance of the drugs, those aspects of drug taking. I was really impressed with that and it did take a lot of time. I had also a session with physiotherapists and also the OT* (Occupational Therapist). *I found that to*

> *be, it was less definitive, less descriptive than what I would have wanted. It was very general and I am sure it would have left neither myself nor anyone else with any real detailed understanding of what patients were supposed to do after they had left the hospital* (M1, 18-25).

> *It was just more or less from different people. I suppose, you know, like the nurses gave me some information to start with and then the visit from the physiotherapist, what you are allowed to do and not, and then the cardiac rehabilitation. You know, they all have pieces of paper. Like they might have only brought three pieces each, but by the time you get all those you know you have gathered up nine pieces of paper!* (M7, 61-63).

> *I recall getting a sort of big talk. They told me that I had been given all these prescriptions. They work a different system now you see. Each department has something to contribute and one lady come*(s) *in and she told me all about diet. Well then* (the physiotherapist) *comes in and she told me about walking and looking after myself and all of that. She seems to have something to do with the heart people* (M1O, 314-318).

Participants with previous experience of hospitals, whether related to their heart or not, were unanimous in their support of the fact that patients are given more information now, and that medical staff are more approachable. There is a possibility however, that in cardiac education at least, it has gone too far the other way. The partner of the man who had two previous heart attacks acknowledged that:

> *We got no information the first time, um but for the second and third times it's been almost overpowering really, too much too quickly* (M4P, 43-44).

The most popular reading material was the 'Have a Heart Book' (Silverstone, 1997). In only 40 pages it has concise information on both hospital and discharge concerns, including risk factors, and tests such as stress tests and angiogram, and includes simple but effective diagrams. There are spaces on certain pages for patients or partners to fill in the recommendations made specifically for them. Examples include filling in dates for where they are on the six-stage treatment plan in hospital, and "your walking programme goals" (p.25) for their programme when they leave hospital. It also contains a blank page for people to write down their concerns or questions. Unfortunately, this booklet is an optional extra which costs the patients $3, the cost representing the cost to the hospital for purchasing these. Providing only this booklet in Phase 1 unless patients request further information may be a preferred way forward in future.

Three participants, two patients and one partner, went to get this booklet during the interview to show to me, and the partner stated that it was good because it covered all areas:

> *You see, it says step by step. I find it covers everything, you see sexual activity, walking, everything. Apart from all the other pamphlets, this is exceptionally good* (M3P, 127-130).

The literature indicates that nurses have doubts about how much information patients are able to absorb and retain during the acute hospital period (Duryee, 1992). This is particularly relevant now that the inpatient length of stay has decreased from an average of six weeks to six days. It stands to reason that attempting to deliver the same amount of information in that reduced time span is unlikely to result in improved communication. Both Chan, (1990) and Steele and Ruzicki, (1987) mention the danger of overloading patients with information in Phase 1.

Another recurring theme in the literature is that information is given rather than patient's receiving individual advice based on their need (Caraher, 1994; Chan, 1990; Murray, 1989: Newens et al., 1997). The emphasis on written material is yet another constant (Murray) but the defence of it as a useful tool to deliver all the information (Allison, 1997) as outlined in the literature review, is not supported in this study. If patients fail to read or comprehend or simply throw pamphlets away, it is money wasted and educational opportunities lost. A more effective approach would be that advocated by Chan (1990) to provide information patients see as important and this may well vary from person to person.

Learning style preferences have been largely ignored, but there is evidence that these are now being given more emphasis in new programmes (Dunbar, 1998; Normington & Goodwin, 2000). The programme set up by Dunbar recognises both the stressors, which can reduce the patient's ability to learn in the acute care stage of illness, and that effective teaching requires an assessment of the individual needs and learning abilities. Their programme and teaching is based around this assessment, which interestingly starts with the very question put to participants in this study, asking about their heart attack and what the experience was like for them.

In Dunbar's (1998) programme there is a questionnaire based on Betty Neumann's nursing model with the aim of identifying "stressors based on the patient's perceptions of his circumstances and help the patient focus on coping mechanisms and relate the circumstances to any previous problems" (p.16D). Initial results are encouraging in terms of patients' responses to this individual approach. The author also makes the point that the nurses have gained an enormous amount of knowledge from the patients.

DECIDING WHETHER TO ATTEND PHASE 2 CLASSES

Attendance figures for Phase 2 education classes produced interesting data even within this small study. All but one of the six men started attending. One discontinued after two sessions because they did not meet his need and one did not go because he had attended the previous year with his wife. Of the five women, only the participant with her sister as a partner attended, one woman had attended the previous year with her husband.

Factors affecting attendance

Although two participants did not attend because they had previously been to classes, in a conversation I had with one of the cardiac educators, she said that she felt this was a shame. From her experience, people invariable did not absorb all the information first time round, and also the programmes were constantly updated.

Access was a major issue for one participant who lived alone some distance from the hospital, and was unable to drive in the six weeks after her heart attack. This did not seem to have been considered by the staff:

> *They had classes and she said "well I hope to see you" and I thought, well, I can't get to any of those (---) I couldn't drive so I had no way of getting there so it was impossible, so I just didn't go* (F9, 226-231).

Two other women lived on their own, but could have taken the bus the short distance to the hospital. In fact one did this already to attend the exercise classes, one of which was held immediately after the education classes, but she could not explain why she was not attending both sessions even though she seemed to recognise that she should.

> *I'm still going up to the hospital twice a week for exercise.*
> ***And do you go to the classes?***
> *No, I'm a bit naughty aren't I.* (F11, 4-6).

One of the participants was a wife in paid employment, and would have liked to go to the classes. She said that her employer would have given her time off, but the time of day for the classes (3-4 p.m.) it was not possible to be away from work; neither was she at home when the cardiac educator visited. She relied on her husband for all her information.

The male patient who stopped attending after two sessions was an articulate patient who wanted to know exactly what he, as an individual, could do to help himself. He did not doubt the sincerity of the staff, but was frustrated by the lack of individual advice.

> *There was a very serious initiative there to make sure that patients are as well versed, and as well informed as possible. I felt that much of it was too general. I would have liked it to have been more specific to my particular case* (big sigh), *but what I had was something that was very general and would have applied to almost anyone else. I wanted someone to tell me what my particular problems were now, and what I needed to do was a, b, c and d. I also would have felt – I needed some checks and balances* (M1, 35-41).

Whilst listing a-d, he counted this off very emphatically on his fingers. He did admit that there might be problems providing individual advice in the classes:

> *We had something like about 24 persons, and there you cannot individualise. And the larger the group, the less inclined people are to open up* (M1, 92-94).

There is not doubt that meeting the needs of a diverse group of patients is difficult, and this was shown by the varying comments from participants. Another patient, who was critical of the classes, felt that the staff presenting each session needed specific training:

> *They are not lecturers, they know their job (---), but they can't hold the attention of the group of people, they are not trained lecturer people* (M10, 344-346).

Later, referring to one specific speaker:

> *The majority of us were left behind. She knew what she was talking about, but she just went too quickly. I said to Mum* (his wife), *that they are not holding the group's attention. Mind you, I didn't put that down on the answer sheet, because I didn't want to spoil the poor girl's job* (M10, 353-356).

There is also an issue here of how accurate the evaluations of these courses are, as even the participants who were critical of the classes admitted that staff were well intentioned. What was highlighted was the problem for staff of meeting the needs of everyone. As an example of this, one felt the staff were patronising, and used this phrase in his descriptions, while another felt they were talking at an advanced level. Comments from other patients included:

> *Some of it was a bit well, common sense sort of stuff I thought. Some of it was a bit, you could say a bit dull, didn't really tell you much* (M4, 190-191).

> *About all I learnt --- the main thing I learned out of the whole series of lectures was that to look for the little red tick on some of the things at the supermarket* (M3, 380-381).

> *I've got the last session to go at the hospital and that's um, nutrition and diet and so on. They've been very helpful* (F8, 302-323).

> *The one of the heart was most interesting (---). The medication was the first one and of course, because I sort of knew some of the drugs and that and <u>that</u> was quite interesting. Um, yes, I can't think what the other ones were* (F8P, 60-63).

> *And we enjoyed the course we went on. We learned heaps and they gave us heaps of books and everything you know* (F6, 359-360).

It is obvious from the few participants in this study that there are issues around both content and delivery of the education sessions.

The problem of low numbers of women attending cardiac education programmes is not a new one, but in spite of this, many programmes continue to be run in ways that do not help or encourage women to attend. Reasons for women not attending include:

- More limited resources in relation to travel.
- The courses remain centrally situated.
- Women can experience difficulties adjusting to their reduced role function (Jensen & King, 1997).

They go on to suggest taking the programmes to women in community based venues and ensuring that programmes are relevant to the needs of women, who often want advice on household activities and resuming sexual activity. Women may be less able to return to their normal activities because their functional capacity is lower even before the heart attack (Loose & Fernhall, 1995). In their study of 98 patients Penque et al. (1998) found that 43% of women and 9% of men lived alone and that those living alone generally received less psychological support and women less financial support, which impacted on their ability and motivation to travel to classes. Apart from women, Gulanick (1998) reported that only one third of the roughly 14 million people eligible for cardiac rehabilitation classes in the USA actually took part.

Despite some of the previously quoted literature that condemns the information giving that occurs on these programmes, there is evidence it still exists. Whilst health care professionals believe "that patient education is a necessary part of treatment" (Yamada & Holmes, 1998, p.3), research has not so far established how patients perceive post MI teaching. What is recognised is that when these programmes were designed, they were aimed at middle-aged men (Moore & Kramer, 1996) and in their research they identified that men and women have different needs in relation to programme content. Yamada and Holmes point out that most studies are quantitative and measure factual learning. Following their qualitative research, they concluded that obtaining the patients' lived experiences of teaching following a heart attack "generated new insights regarding programme delivery" (p.11).

New initiatives are emerging, such as the ones described by Dunbar (1998) and Chu Lai and Cohen, (1999) for inpatients. Outpatient initiatives include a cardiac wellness programme which moves "beyond risk factors," (Leighton, 1998, p.33), and a programme designed specifically for spouses (Norman, 1997) – other partners are not mentioned. These programmes seem more likely to assist patients and partners in the process of adjustment following a heart attack.

The need for more flexibility in both type and place of programme delivery, as well as advocating a graduate programme for nurses in cardiovascular health and rehabilitation is discussed by Gulanick (1998). She also stresses that while many existing programmes are well meant, they are ineffectual and a waste of resources.

SUMMARY

Whilst there is a genuine intent to help patients in the recovery process from a heart attack, the timing and method of delivering the information leaves many patients and partners lacking information that is relevant to their own situation. During the short hospital stay, which incorporates Phase 1 education, patients are inundated with information by different people in the form of reading materials and videos, and this is given to everyone, regardless of their own needs. Partners tend to rely on patients or have to ask for information during this phase. Where individual staff make the effort to communicate effectively with patients it is greatly valued.

Phase 2 education programmes are not well attended by women and once again fail to meet the needs of all who attend, despite the good intentions of the staff. The programmes need to become more flexible in time, place and content, and the problem of women failing to attend may need to be addressed.

Chapter 7

YOU JUST SORT OF BOX ON –CARRYING ON AFTER A HEART ATTACK

INTRODUCTION

The process of living after a heart attack involves patients and partners in coping and making decisions about what they can and cannot do in the days and weeks following discharge from hospital. Some of their choices are based on information they receive and/or beliefs about what has caused the heart attack, while in other areas, their activity is influenced by factors outside of their control.

The adjustment process is greatly facilitated by knowledge, but this needs to be individualised and relevant for that patient or partner. Problems can arise both as a result of poor communication between health professionals, which leaves patients and partners not knowing what is happening or what they can safely do, and the emphasis in cardiac rehabilitation on modifiable risk factors, without considering their relevance to the individual. Once again the role of the cardiac educator emerged as most helpful to patients and partners. An additional issue for partners is the extra demands on their own time as a result of imposed lifestyle changes including hospital and medical appointments.

ADJUSTING TO LIFE AFTER A HEART ATTACK

There is no doubt that life after a heart attack is different to before, and part of this process is learning to cope with the new situation for both patients and partners. Factors influencing how people manage the process of coping in this study were affected by:

- Confusion caused by poor communication between health professionals that impacted on the information patients and partners receive.
- Lack of advice specific to their own situation.

- Patients' and partners' beliefs relating to the cause of the heart attack.
- Life changes over which they had no control.

Waiting for information

An area where the flow of information was disrupted, thus potentially causing problems, with carrying on for both patients and partners was the discharge process. Given that as a measure of their fitness and ability to cope at home patients were supposed to complete the six-stage treatment plan (Appendix A) before discharge, one patient was very surprised to be told before she had completed this, that she had to go home.

> *He came round on the Saturday, he said I could go home today (---) He, Doctor X that I saw first, he said "but she hasn't got to stage six yet."---* (the first doctor said) *"Oh you can go home tomorrow", but really by that I shouldn't have gone home until Monday* (F8, 231-236).

This was the same woman who had her sister as a partner, and the sister reported:

> *She was disappointed about coming out, (---) one day I was there and there was a lady who was going out the next day and the nurse came in and she was talking to her about what not to do and all the rest of it and Elizabeth thought perhaps they would do that with her, but of course it didn't happen like that, because she was meant to go in for six days, and they let her out on the fourth day* (F8P, 211-217).

This also demonstrates some inconsistencies in discharge planning. One of the men who had a spouse who lived in a nursing home during the week and came home at weekends said:

> *Somebody came into the ward to ask if I could manage, I can't remember now, --- but I knew I could manage --- The daughter does what she can, but her priorities are up there now, where she lives* (M10, 513-519).

I visited him on a Friday evening to do the interview, and he was caring for his wife, and had a large bucket of logs by his fire. He admitted that he had brought these in, but not in one large load, as he would have done previously. His idea of managing, and what he should have been doing were, I suspect two different things, but the relevance of his social situation had not been picked up before discharge.

An additional issue worth mentioning for the couple where the sister was the partner, was her lack of involvement in the discharge planning, despite the fact that she was the main carer and visited every day in the hospital:

> *She* (her sister) *must have rung to say she was coming out, but they didn't actually speak to me about it* (F8, 224-225).

Following discharge, poor communication resulted in ongoing lack of information and confusion. Two participants had been waiting three weeks for information.

> *We have been waiting for the report* (of the stress test) *since the 17th and the doctor hasn't even got it yet, so we are hoping to get it on Monday* (F8, 209-211).

> *My doctor is still waiting for a letter of discharge for me and I'm supposed to have one too and neither of us got one. He said ' I don't know what treatment they gave you, I have never heard from them'* (F9, 199-201).

The following participant was still waiting eight weeks later.

> *He was very apologetic last month when he didn't have any further information, but he said he had been trying to get it and they just didn't have the results. If they haven't got it, you can't get it can you? Next week, --- one day* (M4P, 225-228).

In all, seven participants mentioned delays in information being sent to their GPs. There was also evidence of lack of communication between hospitals when more than one health provider was involved.

> *If I can just make one other comment that disturbed me and that was --- I do feel there was a lack of co-ordination between the, --- I was in three hospitals and each of them did not speak to each other about my condition, and did* <u>*not*</u> *I feel communicate adequately with the GP"* (M1, 207-210).

Three patients were waiting for tests when they were admitted with their heart attacks and varying stages of confusion resulted from this. One stated:

> *I waited for about a month or so before I got this information for the exercise test and it was a couple of, --- I had it the previous Wednesday that was the day I had my heart attack. I would have had the heart attack while I was there! ---- and I said it to him* (the doctor) *two or three times, I said, "you know I mentioned about the test I was to have on Wednesday, shall I have it," and he said, "oh, we'll see". And then I asked him on the Saturday (----) he said, " you don't need it" (----) he said "I will cancel it," but he* <u>*didn't*</u>*. And I was having a rest as I usually did after dinner and they rang up and I spoke to her* (cardiac technician) *and I said, "that was supposed to be cancelled." I said I am very sorry, I would have done it myself if I had of realised, and she was a wee bit annoyed to start off with --* (F8, 452-467).

The next patient flew up to have an angiogram and said:

> *The morning I was to have my angiogram and the specialist looked at me and looked at the ECGs, and he said "there is too much mischief going on inside there to think we could ever fix it with a rubber balloon" and he said "there is no point in disturbing it any further at the moment." He said "when we get your diabetes straightened out, while you are at home for a couple of months, and see what happens then" (M3, 56-59).*

Then one hour after his discharge, his consultant from the admitting hospital phoned:

> *Within an hour Dr X rang me and he said, "well I still want you to go ahead and have it and make the appointment," so there I was between one specialist in ** saying we'll wait a couple of months and another saying go. So I thought about it for the night and I then went to see my own doctor and told him the story, and so he agreed with me that what we do is we split it down the middle and go in a month* (M3, 61-63).

Subsequently, the decision was made not to do an angiogram with the result that he and his wife paid for one privately in their bid to seek for answers. His wife had this to say:

> *We were a bit disappointed and the thought of it all being a bit vague, the reason they didn't do the angiogram (----) and although they later said there was too much going on and they said an angioplast was not going to fix it. Until he had the angiogram they really don't know, and they could only know so much from the ECGs and things. The just sort of sent us home again which was ---- and you know there's a tremendous expense with it – and the health system er, they were really just sending you back to square one, because you've either got to have another heart attack or collapse or do something to get back* (M3P, 51-59).

This couple believed the decision not to do the angiogram was influenced by his age.

> *The physician obviously felt he was doing the right thing, although er, as Rob was told, you are 75, you're diabetic, you're yeah ----* (M3P, 68-69).

This was the most extreme case of communication breakdown. Of interest here is that although these patients were waiting for cardiac related tests, it did not cause them to identify that they were having an MI any earlier, as shown in Chapter 4. Most of the participants were accepting of the situation and the fact that the information was not there, but it was obvious that the poor communication was causing distress, ongoing worry and contributing to the uncertainty that Mishel (1990) identifies as disruptive to regaining equilibrium. In the immediate discharge period, there was also the issue of who provided information in this period of need.

SOMEBODY TO TALK TO

Phase 2 education that is for outpatients should begin:

> As soon as possible after leaving hospital and continues for up to the time optimal activity levels are resumed, usually between six and twelve weeks. The length of the programme depends on the specific needs of the patient and their particular cardiac problems (NHF, 1997, p.4).

It aims to "build on the knowledge gained as an inpatient" (p.4) and return patients to an optimum lifestyle including any changes necessary. Without a doubt, the role of the cardiac educator is invaluable here. Two participants were able to compare the pre and post cardiac educator periods for Site one.

The first was the husband who had previously had a heart attack and compared his experience to that of his wife:

> *I think that's a far better system than the district nurses. I had the district nurse, but I think the cardiac educator is better because she's come twice*

> *hasn't she? She came after you came out of hospital and then she came back after you'd been too* (F6P, 256-259).

The next said:

> *We got virtually no information for the first one. We kept being told that somebody would contact us and somebody else would be going through some education assessments on exercise and so on, but nobody ever contacted us. The only person that did get in touch was the cardiac district nurse, and she was available and we had her phone number if we needed her. She was prepared to come out and see us, but at that stage we said well, there is really nothing you can do* (M4P. 36-41).

On the situation with the third heart attack, she said:

> *I got at lot of information from* (cardiac educator)*, um, she was very good, and I think that it was a situation that really needed to be filled. That there was somebody there who you could ring or go and talk to, or who would answer all your questions, and even tell you a few more things you hadn't thought of asking, that was good* (M4P, 180-184).

It is interesting to note that when contacted on the phone, by an unknown person, the participants said they did not need help, but once visited by the cardiac education nurse, they used her as the main source of information.

Another patient who was also a diabetic when asked about the information received at home said:

> *Excellent, the educator was here within a couple of days, no the next day it might have been. She was here and the diabetic educator was here the next day ---. We have since been back and talked to the cardiac educator -*

> *-- and as I say, she rang just a few moments ago to make sure I'm alright* (M3, 83-87).

There was strong evidence of the value of the role of the cardiac educators as providers of individual information and support that facilitates the coping process. A partner said:

> *She's very patient orientated (---). I don't think anyone could ever feel she's not interested in them. She makes you feel you're the only person at the time, and that's a gift* (M3P, 175-177).

One participant was feeling angry and out of control with the whole situation, but the nurse gave her a specific book to cover this:

> (Cardiac educator) *gave me a book by an American woman whose husband has an infarct (----) written from a spouse's point of view, (--) she said in the book that she sort of felt betrayed because this rock at the centre of her whole life had proven to be more frail than she expected and that she found it very difficult, and she had since discovered that a lot of people find that --- spouses find it difficult coping with this situation and that it's tremendously scary (--). By and large it was a very useful book and in it she says that you are going to have these feelings where you just want to go outside somewhere quiet and have a cry and stamp and scream, um kick the cat, or ring its neck or something. You know that if you do have those things, that's fine, it's normal and you are allowed to do that* (M4P, 139-153).

One patient who was discharged before the cardiac educator took up her post went to another centre for further investigations and told me:

> *I don't know if it is possible to be <u>that specific</u> in each particular case, but in fact that is what I have asked for now in contact with the cardiac*

> *rehabilitation nurse from ** who is going to make me a very detailed programme. One that is exclusively for* *__my__* *--- to treat my particular condition and I feel a lot more confident* (M1, 44-48).

This example of providing specific information to meet individual need is likely to greatly assist the recovery process and adaptation, for both patients and partners, but it does involve skilled personnel.

Several participants encountered unnecessary worries following discharge home, or when transferring to other hospitals, because information relating to their care had not been passed from one health professional to another. Discharge planning is a complex area as identified by Hedges, Grimmer, Moss and Falco (1999). They suggest introducing performance indicators to help overcome the problem.

In the literature review, four studies were cited that identified a gap in information needs that occurred between discharge and Phase two education programmes starting. Two of these found that this is the time when information is most needed (Dracup & Moser, 1997; Thompson & Cordle, 1988). The need for information as an essential stage in the coping process after a heart attack is recognised be several writers (Keckeisen & Nyamathi, 1990; Nyamathi, 1987; Theobald, 1997; Yamada & Holmes, 1998). Rehabilitation of the patient is greatly assisted if partners feel well informed and supported (Kettunen et al., 1999).

SEARCHING FOR THE CAUSE OF A HEART ATTACK

There were two areas where patients searched for a cause of their heart attack, the first being what they were doing at the time and the second, relating to modifiable risk factors. This search remained ongoing at the time of the interviews and is obviously a constant process. What they believed had an impact in terms of decisions they were making about how to live their lives in future.

Activity at the time of the heart attack

> *When I had it, I was actually watching somebody else work. I wasn't actually doing anything* (M7, 16-17).
>
> *It's only a little kitchen, wouldn't even be as big as my kitchen, and I just stripped some wallpaper, whether it was reaching up---* (F11, 268-269).

In this process of searching, problems may result for patients like M7 who was not doing anything that could account for his heart attack occurring at that time. This could result in work being seen as the cause of the heart attack. In fact later on he alluded to this. His GP had told him he could return to work, but his response was:

> *I am really in no hurry to get back, because I don't want to rush anything. Um, I don't want to go back now and have another one* (M7, 136-137).

Another patient who had a job with long hours indicated that he would be changing his work and had *"just a small job jacked up"* (M5, 180). Finding the correct level of activity was a problem identified by several patients and an area where there was obviously some confusion.

> *I said* (to another patient at the rehabilitation classes) *it's driving me nuts, I don't know how you do it. She said just pretend you are on holiday. I said but you are allowed to do things on holiday!* (M7, 142-144).
>
> *I find this sitting around being quiet a bit much for this nut case* (M3, 152-153) (---) *I quite enjoy life, but you can't sit around forever after a heart attack. I know it's a dream when you are young, when you experience it you don't really want it* (M3, 156-158).

Another example was provided by one of the women:

> *You can't wrap yourself in cotton wool (F11, 181).*
> and later; *what do you do, you can't sit in the corner all the time can you? Let's face it, you know, I sort of sit here at times and think well, what am I supposed to do* (F11, 285-287).

One patient whose discussion provided the title to this theme summed up how several patients seemed to feel, which was confusion about how much they can and can't do and results in the process of boxing on, or coping as best they can. Because of a bad back, his activities before his heart attack had been reduced, but now he described how he and his wife who had also had a heart attack:

> *Just sort of box on --- but we do try more walking and that now* (M6P, 216-218).

Some patients found themselves initially having to reduce activity as they were so tired, and this represented an enforced change in lifestyle that they perceived as outside of their control.

> *I have been unusually having a lie down in the afternoon for an hour, not actually sleeping and not for very long ---* (M3, 48-49).

> *One of the major ones* (changes) *is, that I have been forced to take, is I have a lie down every day at lunchtime, and that's something my wife supervises* (M1, 184-185).

> *And sometimes when I think about going* (for a walk) *I am tired and it is no good going* (F8, 384-385).

> *That's another thing that I did notice when I came home (---) I was having a morning and afternoon rest. Anyway I was up at my daughters so she*

> *said "come on Mum, it's time for your rest." I said, "oh look, I'm never going to get strong," I said "all I'm doing is sleep, eat, sleep and eat" (--). So anyway, I go in and because I'm not one to lie around all day, look I was going into a deep sleep, I really did* (F11, 531-537).

Some patients adopted a strategy of doing too much, even when they knew it was not wise.

> *I had done a lot more than I should of, I was painting the house, had to keep things happening, so I mean I shouldn't have been doing that* (M5, 166-168).

One wife described her husband's activity in the garden:

> *He still had enough in that to feed the five kids when they were at home you know, and I just get irritated because he gets one lot thinned out from down there, pickled and sauced and whatever, and the next thing he is carting another lot, I don't need that. I just can't get it to sink in* (M4P, 102—105).

This was also creating extra work for his wife who was already concerned about the situation and was trying to watch her husband to see he did not overdo things.

> *I find the uncertainty of it a bit nerve racking at times, particularly if he sort of looks a bit tired. I think he is losing vital signs. I'm sort of trying to spy on him without him knowing* (M4P, 261-263).

Her husband retorted from the kitchen, where he was making a drink:

> *"She's watching me like a hawk"* (M4, 263).

Her immediate and very sharp response was:

> *"When you are out in the garden digging, I have to come and make sure you are not dead amongst the cabbages. I can't help that, that's just me and you are going to have to live with that"* (M4P, 264-266).

Another wife said in her written feedback after the interview that:

> *I was concerned with Bill mowing lawns as I thought it was too soon to be doing jobs like that* (M7P).

These feelings could have the potential to disrupt partnerships, particularly if the patients feel partners are constantly watching them. Interestingly, one patient had earlier acknowledged that the situation could be more difficult for partners, while his wife said:

> *It would be almost easier if I was him* (M4P, 121).

Other participants demonstrated some evidence of this concern, but it was not as marked. It is not difficult to imagine that this anxiety is common to a greater or lesser extent in many partners. That it was an ongoing problem for this one partner was shown through her observations throughout the interview.

> *You can't get your knickers in a knot. You only drive yourself crazy worrying unduly* (M4P, 29-30).
> *I have learned to live with it: I think you have to* (M4P, 31).
> *(--) but it does take some working through* (M4P, 33).
> *He seems to be alright, I am <u>concerned</u>, but I am not paranoid about it or anything. It's something he's going to have to learn to cope with (---). I try not to boss him too much* (M4P, 83-85).
> *I will have to learn to live with it* (M4P, 119).

Although she referred to "learning to live with it," it was obvious that she was still engaged in a struggle to do just that. The helping role of the cardiac education nurse was demonstrated when she recalled how:

> *There was somebody there who you could ring or go and talk to or who would answer all your questions and even tell you a few more things that you hadn't thought of asking, so that was good* (M4P, 182-184).

To a lesser degree, other partners indicated that there was an ongoing concern about how the patients were managing which brought with it conflicting emotions in the adaptation phase.

> *It is a traumatic experience, even though you have sort of faced the possibility. But, er, we are getting older and these things happen don't they, to one or another* (M3P, 181-183).

> *The night before last she said, I don't think I will have a bath tonight. She always has a bath at night, and she had pain in her back and I think she was pretty tired or something, so I just wondered if she was okay* (F8P, 9-12).

What is obvious from this data, is that while advice is given on exercise that fits into an exercise programme and is discussed further on in this chapter, there is considerable confusion about how much and what activities patients can undertake. Apart from activity and how patients felt, the main influence at this time was modifiable risk factors, presumably because of the emphasis given in the cardiac education programme in Phase 1.

Risk factors

Patients identified three main modifiable risk factors in their search for a cause of their heart attack, and these were stress, diet and exercise. Examples of stress being identified as a cause of the heart attack included:

> *Whether I've been a wee bit stressed out, I don't know. But as I said to my daughter, "how do you know when you're stressed out?"* (F11, 308-310).

> *And of course with the stress of the business and everything, it withdrew the potassium* (M5, 39-40).

This patient came up with this as a cause because of information he had been given by the doctors in hospital.

> *He* (the doctor) *said, "what pills are you on?" (---) and he had a big thick medical book and he went through it and found it. He showed it to me, where it feeds on the potassium level in your body* (M5, 34-36).

Sometimes the search involved other people providing the ideas. One female participant telephoned her sister when she was discharged.

> *I was interested to see what brought it on and she said, before she had even spoken to me, stress on the house not selling, money situation and that's what it is* (F9, 105-107).

Diet and exercise were areas where there was confusion. While a few patients learnt from the advice, it was the generic delivery and lack of individualising that caused problems. Patients who had already made changes to their diet and exercise regimes were simply frustrated that they were unable to identify a cause that they could do something about.

> *Well, they talked about diet, although I think we have a good diet. My wife has been watching it for years as far as fat and stuff go you know, we don't cook in fat and we don't eat butter, we have lean meat* (M4, 72-74).

> *I still feel that ----- not really angry but just a bit annoyed, that he has managed to have three heart attacks when really he has never done*

> *anything, you know, he has been one of those people who has low fat diets* (M4P, 72-74).

This wife was angry particularly as she was unable to identify a cause. She also articulated how her anger stemmed from lack of control.

> *But I find it a bit difficult because I'm one of those people who likes to be in control of my life, and I am not anymore and I find that very difficult* (M4P, 117-118).

This was the couple where the husband had had three heart attacks. They had adjusted their lifestyles and yet not been able to prevent further heart attacks, hence her comment on control. Another wife said:

> *We are already into the routine with the diabetes and the fat, because we knew, I mean with the angina, I knew that he must --- that we should cut down on the fat, so we haven't fried anything for years you know, and I used to cook the mince and strain it through hot water and did all those things before all this* (M3P, 146-149).

Her partner said:

> *She* (the dietitian) *said "well I will have to first of all to (---) compliment you on your diet." She said "your cholesterol is fine and your lipid is 2.8 and it should be 3" and I have forgotten what the bottom one was. She said, "obviously your diet has been pretty good." That was a couple of days after the heart attack. So you know, my wife's well aware of it, but all this probably has done is a touch reduce quantities, but not any basic changes* (M3, 145-150).

Of the patients who were going to make changes M7, whose heart attack had been put down to family history for lack of any other cause, said he would be looking for food with the NHF "tick" on it, and drinking a glass of red wine, which he did not like. Looking for food with the tick was mentioned by six participants and this obviously helps people when out shopping. F6 and her partner said that they were going onto half fat margarines, calci-trim milk and cooking oil, but admitted that they were *"still not really good"* (F6P, 185). While one man said:

> *Everything we eat now is from the Heart Foundation with the tick; fruit and veges every day, both. I live on fruit and veges just about you know (M5, 149-150).*

The advice is relevant for some people, but not for those who have already changed and the whole emphasis appears to be on fat and sugar. The problem remains lack of individual advice, another example of this being one patient who told me the she had to reduce sugar as it was harmful:

> *I bought some crystallised ginger and the banana chips which I like, but you see they're both no nos and I thought oh, (---) it was only at night and sometimes through the day I might have a nibble* (F11, 222-223).

It is unlikely that a few banana chips or pieces of ginger would be harmful, but she has taken the advice as meaning she can have no sugar and is in fact making herself miserable. She went on to say how she used to eat the banana chips or ginger:

> *I would get so much and put it in my little jar, but I didn't sit and gorge on it, and um, so since I've got nothing to nibble on* – (F11, 238-240).

Now when she feel like a nibble she has a little yoghurt, which she obviously does not enjoy much, this has the potential for her to revert back to her old eating habits, whereas a compromise and individual plan might have helped her more. In one study, 20% of wives (n=113) reported that dietary management was a concern and that what they wanted was more specific information

(Bramwell, 1986). While there is undoubtedly more information now than in the 80s, it still appears to be non-specific. Another problem areas is advice on exercise.

Exercise in this context, is different to activity as discussed earlier, in that patients are instructed to exercise in the form of walking during the Phase 2 period. Activity was earlier used to describe everyday activities that people expect to be able to carry out, such as gardening and housework. I would argue that an exercise plan should look at these two areas on an individual basis, particularly as they are the most common exercise activities undertaken by most people.

Four patients said that they had been advised to walk three times a week but went every day. There was probably no problem with this, but they all voiced uncertainty as to whether they were doing too much. Individual advice, taking into account patients who enjoyed walking as opposed to those who needed to be told the minimum recommended amount would be better.

One patient showed how generalised advice could be useless on an individual basis. He had been told to increase his walking gradually and by the second week to include some hill work. His house was on a steep hill, so whichever way he went out he had to climb a hill, either leaving or coming back. He had set his own targets of increasing lamppost by lamppost, accepting that he always had a hill to climb.

One woman had leg ulcers, which had reduced her mobility for the last twenty years, but the message to exercise spurred her on to try harder.

> *I decided to walk down the road to ** highway, and Kate was coming in the car and I got so far and I thought well, I'm not going to sit in the gutter. I leant against ---- it was a big high fence, and I just used my spray. She came along a short time after* (F8, 376-378).

This coincidentally was the patient who was discharged early before she had completed the six stages, the fifth one of which is climbing a flight of stairs without becoming breathless. Patients make decisions on a day-to-day basis and it is possible that they forget some of the information, especially if it is not reinforced in the post-discharge period. This is where the Have a Heart booklet (Silverstone, 1997) is useful, with its advice on activity, and gaps for the patients to write notes relevant to their own situation.

Only one patient admitted to not following the advice on exercise. The emphasis exercise is given seems to have the desired result, at least in the short term, but as has been shown, not always in the way envisaged by the health professionals. Individualising advice and taking into account, where people live, their previous health and what they expect/would like to achieve might be a more effective way of helping these patients. There is a standard regime for increasing exercise, and it is also written in many of the pamphlets and literature that patients are given, but obviously patients have some difficulty relating it to their own situations, or in some cases have not absorbed the information.

> *She said, "well don't forget to do your exercises" and away she went, and I thought what exercises?* (F9, 124-125).

This same patient subsequently tried to do too much in terms of walking on a windy day, although one piece of advice, which is written down, includes the reminder to take care when walking in windy weather.

> *I walked all the way into town the other day to the doctor's and I got there and could hardly breathe. It was that windy and it was the only way I could get there. I perhaps should have got a taxi, but I was walking into the wind and by the time I walked home, my house was getting further and further away, and I was getting slower and slower* (F9, 126-131).

This illustrates another major concern, especially for women and that is the restrictions on driving immediately after the heart attack. This will be discussed further on.

All the participants in this study alluded to one or more of the modifiable risk factors in their search for a cause, and both patients and partners undertook this search. What is not known is how many of these risk factors they were aware of before their heart attack, as much of this information could have been gained before, during and after hospitalisation. Some people are unable to identify an obvious cause of their heart attack.

NOT BEING ABLE TO IDENTIFY A CAUSE

Patients who are unable to identify a modifiable risk factor as a cause had to look elsewhere for a reason for their heart attack and these were inevitably non-modifiable risk factors such as family history.

> *We've got a brother who had a heart attack and then his wife, (--) but now that Elizabeth has had this she's sort of ----you know it makes more sense* (F8P, 136-138).

Her sister (the patient) had a different theory having had arterial surgery on her legs.

> *I wouldn't be surprised if it was something to do with the hardening of the arteries myself, but I could be quite wrong. Can't do anything until we find out* (F11, 471-472).

Hardening of the arteries could result from a modifiable or non-modifiable cause. This also highlights the problem for patients who are unable to identify or accept a cause, the very ones for whom the search can fail to provide answers.

> *I don't smoke, I'm not overweight, my cholesterol's O.K., no stress, no blood pressure and that's what they do, they just put it down to family history, because they can't find anything else and both my parents had heart attacks and they are putting it down to that* (M7, 44-47).

Having a family history is outside the control of this patient. The only thing he could do is control other risk factors to minimise risk, but he has already identified that this has been done. When asked if she had identified any factors that could have contributed to his heart attack, his wife said:

> *You wish you could really, --- wouldn't you think, don't you -----* (M7P, 35).

A difficulty for these participants is that they cannot identify definite positive changes that they can make, while those with modifiable risk factors can. Some participants had problems accepting it had happened at all, because they could not identify a cause.

> *That's what I say, makes you wonder what you* (ve) *done to deserve it really* (F11, 473).

> *So I sort of think, well you know, I get a bit peeved that --- why him?* (M4P, 81-81).

This searching for a cause is variously discussed in the studies of patients who have had a heart attack. Cowie (1976, p.95) found that the ability to identify a cause made the experience "intelligible" to patients, while failure to identify the cause led to patients claiming not to understand why it had happened. Scherck (1992) reported that there was a sense of control in identifying a cause. She found that self-blame was a positive feeling as it led to patients being able to make changes. This does not account for patients who self blame but cannot recognise areas for change.

In their study Johnson and Morse (1990, p.128) use the "struggle to regain control" as the central theme for post heart attack patients, and describe the search for a cause as necessary to make sense of a heart attack. All the participants in their study believed lifestyle factors caused heart attacks, even when they could not identify any areas of inappropriate lifestyle in their own lives. Johnson and Morse concluded that this search forms part of the adaptation (and therefore coping) process after a heart attack.

Lowery et al. (1992), identified patients who did not search for a cause and who were termed deniers and those who did search were found to be more anxious than the deniers. Another perspective provided by Ben-Sira and Eliezer (1990) is that there are demands, which they define as any stimulus, requiring a response and that if demand taxes or exceeds the resources available, they become stressors, which in turn reduces the capacity to adjust. Partners adopt various coping strategies. There are two different strategies of "active engagement" whereby patients and partners share in problem solving and "protective buffering", where the partners hide their worries and do not share concerns with the patients (Coyne & Smith, 1991, p.405) which can result in over protectiveness. This over- protectiveness is described by Riegel and Dracup (1992) as beneficial to some patients and as a way to manage uncertainty by Theobald (1997).

Factors which can affect the patients' coping mechanism include a "perceived lack of control over destiny" (Keckeisen & Nyamathi, 1990, p.32), and certainly this would occur if patients are unable to identify things they can do to reduce the chances of another heart attack. In her study of 30 patients, Scherck (1992) suggests that patients use varying coping strategies, suggesting a "coping process that differs from the widely accepted anxiety–denial trajectory model" (p.330). She feels that patients view life as a challenge, part of which is recovery and the other part lifestyle changes to prevent recurrence. Patients in this study, who would be termed deniers under much of the existing literature, could be viewed under Scherck's model as meeting the challenge by pushing themselves to do too much.

Scherck (1992) goes further in suggesting a major role here for nurses in identifying and facilitating different coping strategies that people can use. She acknowledges the need for more studies on this. She hypothesises that all patients do not have the same perspective post MI, which is an assumption in many of the earlier studies such as Johnson and Morse (1990) and Cowie (1976). She found patients willing to describe what they think about the situation if nurses only ask. That was also my experience, and certainly all participants did not have the same outlook during the period after discharge. I would agree with Scherck that there is a major role here for nurses to listen to and base rehabilitation around the needs of the individual. This is supported by Keckeisen and Nyamathi (1990), who identify nurses as able to enhance psychological and social outcomes in these patients.

Scherck (1992), suggests that anxious patients might need distractions so that they do not think about their illness so much, while others need rehabilitation information that enables them to set up a "specific action plan" (p.333). In other words nurses need to identify whether patients' and partners' coping strategies are primarily emotional or problem solving as discussed in the literature review. It is possible to identity both groups in this study. A typical example of the latter was M1 who said:

> *I would really like a very detailed prescription of what I have to do, not so much to prolong my life, but to get back to a state of* <u>*wellness*</u> *that enables me to enjoy life. I am much more conscious of being in a position of being able to enjoy life rather than to prolong it. I am not so interested whether I am going to live from 75-85, that is really very impractical. It's quality, I really don't want --- It's the prospect of just lying in hospital or the prospect of being disabled in some way or another* (M1, 198-204).

The problems caused by uncertainty in the coping process are indicated below.

> *These ones say you shouldn't do this and you shouldn't do that, but your life's still got to carry on* (F11, 294-295).
>
> *Well, you sort of think you should be doing that and that and then she sort of lets me know how she feels, no, it's er, well, you're always glad when you get the reports and things like that* (F8P, 240-243).

The patient with the invalid wife had fitted his heart attack into his framework of life. They were an obviously devoted couple, and I wondered whether his attitude and having no regrets about his past life had affected his coping. He had also been diagnosed with cancer after his heart attack and was waiting for further tests. At the end of his interview he and his wife showed me family photos and told me the story of how they first met in their teens. He appeared to have emotionally adjusted to what was happening:

> *Our health is packing up now; we knew it would. I mean I'm 78. We knew that eventually we would crash. (---)*
> ***It's such a shame because you've got two health problems now.***
> *Well yes, but we have had a <u>marvellous</u> life. I built this house and we got married in it* (M10, 655-659).

The different outlooks and goals of these participants highlight the need for individual strategies within their rehabilitation programmes and not necessarily aimed at modifying risk factors. The patient quoted above would be a good example of how the mechanistic paradigm does not fit with the aims of all participants. He had not given up smoking and was not exercising, but was at peace with himself, and realistic about his future health outcomes and the reality that this might include dying.

Apart from the cases already cited in the previous chapter on new ways to organise cardiac rehabilitation, Caraher (1994) supports changing the way patients are educated and Dunning and Martin (1998) suggest building individual education initiatives according to a person's frame of reference. This would in fact then encompass their individual coping mechanisms in line with Scherck's (1992) findings.

On the subject of risk factors, "The Holy Trinity" (Nettleton, 1997, p.319) referred to in the literature review appears to have become the Terrible Two of diet and exercise, regardless of whether is it needed for that individual or not. As one participant said when recalling information he had been given:

> *Oh, diet of course; I keep hearing diet and exercise* (M4, 165-166).

Presumably smoking does not have as much emphasis because this message has largely got through to this age group at least, and is comprehensively covered in population health programmes. Only two participants in this study smoked and New Zealand smoking rates are lower than Australia (Jackson, 2000).

For both patients and partners, the mechanism of coping after a heart attack depends on which strategies they use to cope and this in turn is affected by how much control they feel they have over the situation. The information they do or do not receive impacts directly on these coping strategies and their adjustment to living after a heart attack. Other factors that may influence this process are changes that are unavoidable and outside people's control. There were two main areas identified. The first was not being able to drive for a few weeks after the heart attack, of particular relevance to patients living on their own, who in this study were all women. The second were the changes imposed on partners in the rehabilitation process.

IT'S NOT BEING ABLE TO DRIVE

In these years of car ownership, not being able to drive for 6-8 weeks was mentioned by two partners and three patients, but in different contexts. Health professionals may not consider the impact being unable to drive can have on individuals. Apart from problems accessing cardiac rehabilitation, as already mentioned, the car can be a lifeline, particularly if patients live on their own in a rural area. One woman described the impact on herself as follows.

> *Actually, it's not so much the heart attack; it's not being able to drive. You lose your independence, my daughter used to come and take me to do my grocery shopping and that was fine, but she said, "oh, when we're going out tomorrow I will take you for a drive." Well, they forgot me, and I was devastated that nobody came, you just get sick of it* (F9, 134-138).

Interestingly, one of the other women who lived on her own had already moved to town in anticipation that her health might deteriorate. She had actually been asked how it would affect her, and there was some ambivalence in her feelings as reflected in her story.

> *If I wanted anything, I had to get my granddaughter, but she didn't mind doing it. But when you have got your independence, because they said how are you going to get on if you can't drive. I said "well, look it's not worrying me" and it didn't because I know that there will always be someone to get my bits and pieces, because it was pointless. I wasn't allowed to drive so and I mean when I moved here, that was my general idea, that one day I might not be able to drive. I didn't let it get on top of me, and as I say, I found the days long because I was home here ----* (F11, 166-174).

In the 50 plus age group in particular, men are often the traditional drivers when the couple go out together, even if the wives are able to drive. This has the potential for conflict that could relate to role changes.

> *The most difficult part was when he first came out of hospital because he wasn't allowed to drive. He hasn't made a very good passenger, I might tell you* (M4P, 232-234).

Her husband did not mention not being able to drive the car, but had a motorbike that was obviously one of his main hobbies and pleasures.

> *Leaping on my motorcycle and going for a ride --- that's my toy (---). They said "you can give that away for eight weeks!"* (M4, 87-93).

It is doubtful whether partners who drive have any choice in this new demand on their life and having a partner who had just had a heart attack is not a time for confrontation. Whilst it is a short-term problem, it occurs during the immediate discharge stage, when stress levels may well be raised. This is also the time when patients have most need of transport for doctor's visits and cardiac rehabilitation courses. An additional issue is the impact on partners of taking over the role of chauffeur and therefore having to accompany the patient everywhere.

IT'S A CONSTANT TREK

There was evidence of increasing demands of partners, both associated with having to drive patients everywhere, and in other areas.

> *I mean, one day we had three visits up there* (the hospital) *(---) and I find that a bit much. I know it was only one day and it was mainly because of the ultrasound* (which was related to a different health problem)*, um, but we had a couple of times where we had to go up twice a day for different things and we have got to go back and see the specialist next week (---) so it's a constant trek and I think that if you are a patient, you might get a bit tired as well because it's not all that very long ago, what --- about five weeks* (M4P, 207-214).

This couple attended the cardiac education classes, which were some of the visits, and there were also visits for blood tests. It was complicated because the patient had developed another health problem and was also seeing another specialist, but there was no liaison enabling them to combine visits where possible.

The participant who was the sister of the patient was the only driver of the two, but there was obviously a marked increase on her time in terms of driving.

> *And then of course, she doesn't drive and I always am going to the doctor, (---) it takes up the time going in and out, I just thought the other day, well what did I used to do? There was quite a number of ones I used to visit, and I haven't got so many friends perhaps who like a visit, so I suppose this had sort of been taking my time instead* (F8P, 73-81).

Trying to maintain their own lifestyle involves partners in choices, as well as decisions, over which they have no control. One wife admitted she had not attended a cardiac support group with her husband because:

> *It's not that I wouldn't go --- it's just that I have my own commitments and um---* (M3P, 105-106).

It would seem that the needs of partners are being sublimated to those of the patient and in some ways, the medical and nursing staff are condoning this. For some partners it is obviously an additional stressor in this period of adjustment. This links in with the findings by Dickerson (1998), mentioned in the literature review, that partners' needs are often overlooked in favour of the patients. These types of demands on lifestyle are described as being imposed by a medical regime (Ben-Sira & Eliezer, 1990) and are behaviour changes outside the control of the individual.

> *We have, oh for quite a number of years had a week about doing cooking you see. But of course, since she, well, she has, um, yes week about --- but standing at the bench sort of gets a bit tiring, but it's my work at the moment, but er, she has had a go and then perhaps I can just help out as needed ---* (F8P, 99-104).

And later:

> *Because the thing is we sort of do our own jobs more or less. The washing and putting on the line has always been her job, so I did it to start with, and then she said I think I can---* (F8P, 247-249).

Other examples include:

> *Even my wife has made lifestyle changes too. We have toned down our entertaining (---), so yes, things have changed* (M1, 193-194).

A wife identified the uncertainty of not knowing what changes might occur:

> *The thing that is going to affect us is that if he doesn't go to work. I mean it's not my choice (---) you know if he changes* (jobs) *what he wants to do* (M7P, 87-89).

The literature overwhelmingly supports the importance of the role of the partner (usually the wife) in facilitating the recovery of the patient (Beach et al., 1992; Dickerson, 1998; Ell, 1996; Moser et al.1993; Theobald, 1997). Several studies also acknowledge the lack of support for partners even while identifying their need for information. In addition to this, the study by Moser et al. found marked differences in the informational needs of spouses and patients and that a priority for spouses was to have some time alone and to be able to be away from the patient without worrying.

There is also evidence of social isolation (Ell, 1996), which is hardly surprising given the time partners may have to devote to the patients. Theobald (1997) found that spouses are "neglected within the framework of cardiac rehabilitation" (p. 600). This means not only their educational, but also their psychological and social needs.

A pilot programme organised for spouses (Norman, 1997) included discussion and sharing of problems, as well as practical advice on recipes and cooking (rather than advice to simply reduce fat and sugar), the benefits of exercise and simple relaxation methods all of which would improve their ability to cope. All the wives taking part found it beneficial and the programme continued to be run. There is a need for more emphasis on, and research into, the needs of partners and also women living on their own.

SUMMARY

The lack of individual information and education programmes results in the process of 'boxing on' whereby patients and partners cope as best they can with the knowledge available to them in their efforts to carry on with life. The post discharge period has been greatly improved by the role of the cardiac educators, who appear to meet the individual needs of patients and partner, but their role and effectiveness is reduced by the contact time allowed for each patients and partner.

The failure of health professionals to communicate with each other, and the general giving of information in cardiac education programmes result in gaps in patients knowing what they should be doing, and this is likely to affect individual coping strategies. The emphasis on controlling modifiable risk factors for patients who have already done this results in frustration and anger for some patients and partners, as they are unable to easily recognise a cause of their heart attack, and subsequently have problems identifying what they can do to prevent another one occurring. An additional issue is the emphasis on walking as exercise, but a lack of advice relating to other everyday activities.

A problem for partners trying to adjust, is the increasing demand on their own time in the early discharge period, and a lack of specific support. Patients and partners will have different needs and employ different coping strategies in the early rehabilitation period, depending on their frames of reference. There is a role here for nurses to individually assess these needs and listen to what patients and partners are saying to facilitate the whole process of adjustment and living following a heart attack.

Chapter 8

DISCUSSION AND RECOMMENDATIONS

INTRODUCTION

This chapter discusses issues arising within the four themes identified from the data. Experiencing a heart attack is often an insidious event involving a variety of non-specific symptoms, and as a result, people do not seek help until hours or days later. For women, there is an additional problem that even when they do seek help, medical staff often fail to recognise that they are having a heart attack or acknowledge their need for pain relief. This raises educational issues relating to increasing professional and public awareness of signs and symptoms of a heart attack.

Cardiac education programmes in this study were shown to follow the traditional model of education. Whilst patients and partners receive a great deal of information, especially in hospital, the lack of individualising it results in patients and partners not gaining information specific to their needs. Cardiac educators were identified as a most useful source of information in the post-discharge period, and it is suggested that changing the focus of when and who delivers cardiac education may be beneficial.

DISCUSSION RELATING TO THEMES

The aim of this study was to find out what information patients and partners wanted following a heart attack. The use of semi-structured interviews for collecting data and thematic content analysis to interpret resulted in the identification of four themes by the researcher. These were:

"It wasn't too dramatic", and this was the experience of the heart attack, which relates more to the patients than partners.

"They didn't even think it was a heart attack", which reflected differences in how women, as opposed to men experience a heart attack, which in turn results in the failure of medical staff to recognise that women are having a heart attack.

"Tell me what my particular problems are", which covered how, when and what information patients and partners received and whether it met their needs.
"You just sort of box on", which was the process of adjusting after a heart attack. There was evidence here of how information or lack of it could impact on this process. Each theme raised different issues for discussion.

It wasn't too dramatic

This theme showed how a heart attack is insidious in onset and rarely dramatic, despite some suggestions in the literature to the contrary. The commonly held belief that people deny they are having a heart attack is also questioned, as it appears that often they genuinely do not recognise what is happening to them. As the woman who drove herself to the GP said:

> *I wouldn't have done it if I thought it was a heart attack* (F11, 16).

The retrospective nature of research into the experiences of a heart attack means that it is difficult to judge what patients really felt. Two authors who state that recognition of a heart attack is not easy especially given the variety of symptoms experienced are Cowie (1976) and Scherck (1992). The gradual onset of symptoms and non-dramatic occurrence results in delays in people seeking help as was shown in this study, and is reported in the literature discussed in Chapter 4. It is only when symptoms become severe enough to interfere with normal activities that people seek help.

It is difficult to suggest a way around this dilemma. Reducing risk factors is a major aim of governments seeking a reduction in IHD rates. Part of the process of reducing mortality and/or morbidity by minimising the damage to the myocardium depends on receiving thromboembolytic drugs within 12 hours of the onset of pain (Meischke, 1999; Pearson, 1999b), yet this aspect is not addressed in health promotion strategies. Including education to patients on recognition of signs and symptoms of a heart attack so that they may present earlier is suggested by Alonzo and Reynolds (1997), but could be difficult to implement. This study showed how tiredness was often an early warning sign, and it is likely that many people experience this at some time in their lives without it being an indicator of a heart attack. Additionally, the variations in types and sites of pain could make it difficult to prepare people, as contrary to popular belief, there is a lack of standard presentation confirming a heart attack. It may be that more could be done to alert "at risk" people being treated for hypertension or diabetes, but this would need to be done without causing undue alarm. For women there is also an educational issue, particularly in relation to seeking help earlier, if the type and intensity of their angina changes.

They didn't even think it was a heart attack

In this theme, women described their frustration in trying to obtain a correct diagnosis and also adequate pain relief. Women have a double issue of delay in seeking help combined with the failure of medical staff to make a correct diagnosis when they do seek help. Literature that has provided the framework within which doctors' diagnose a heart attack, is built on studies almost inclusively involving men (Johanssen et al. 1983). In the most comprehensive study involving men and women, the Framingham study Kannel and Feinleib (1972) reported that more women than men present with angina, but less women than men with angina present with a heart attack. The more recent recognition that women's risk increases after the menopause (Jensen & King, 1997) and the upper age limit for participants of the Framingham study being 65 years, may account for these findings.

Other literature reports that women may present with different symptoms (Benson et al., 1997; Travis et al., 1993). Interestingly, Penque et al. (1998), in a research study with sample of 52 men and 47 women, concluded that chest pain was the most common presenting symptom for men and women, but women often experienced variations in the associated signs and symptoms. Significantly, their research identified major differences in therapeutic courses between men and women, specifically the "women were under treated" (p.181), which also occurred in this study.

Educating women, both into their risk of suffering a heart attack and symptoms they might experience is advocated by Meischke et al. (1999) and Penque et al. (1998). There are the same issues as before on education relating to symptoms, but increasing the awareness of women to their risk of having a heart attack, particularly after the menopause, would seem a useful health promotion strategy. In New Zealand, posters presently exist warning women of the risks of breast cancer, similar ones relating to the risk of a heart attack after the menopause might be helpful. Additionally further research into the attitudes of medical staff to women experiencing a heart attack is recommended.

Tell me what my particular problems are

In the literature review health promotion was briefly discussed and whilst cardiac rehabilitation is widely viewed as a heath promotion strategy its main focus is cardiac education. The varying definitions in Chapter 2 show the emphasis on improving and/or returning to active life following a heart attack, and in the case of the NHF (1997) promoting secondary prevention.

The present emphasis on the lifestyle theory of disease has resulted in a focus in cardiac education on reduction of risk factors and many of the programmes follow the traditional educational model rather than the participatory model (Latter et al., 1992). Whilst the NHF (1997) aims for Phase 1 and 2 of these programmes to include consideration of individual needs, the descriptions from patients and partners show that the traditional delivery style used in these two sites result in an overwhelming amount of information being given to patients which does not always meet their needs and which they cannot always absorb. As far as partners are concerned, there is evidence that they sometimes need to seek out information in Phase 1, although they acknowledge the wealth of information handed out to patients and how overwhelming it can be:

> *It's been almost overpowering really, too much, too quickly* (M4P, 44).

It appears that the aims of inpatient education of the NHF (1997) as given in Chapter 2 and which relate to education in Phase 1 are over ambitious. This phase overloads patients with information at a time when they are not equipped to take it all in, and ignores the work of Chan (1990) and Steele and Ruzicki (1987) who both highlight this as a problem in this phase. It may be that this situation has arisen as the inpatient period for these patients has decreased (Scherck, 1992).

There was evidence in both Phase 1 and Phase 2 of the education programme, of different methods of delivering information, verbal, written and video, but the greatest emphasis remains on written and different health professionals often duplicated this especially in Phase 1. This study also showed evidence that partners are not always provided with information which will help them fulfil their important role in the recovery process (Coyne & Smith, 1991).

The cardiac education nurses were recognised as an important source of information and demonstrated a more participatory model of health education, which was more suited to meeting the information needs of individuals as demonstrated by the quotes from patients and partners. The cardiac education nurse appears to met the requirements of the 'helpful person (Dickerson, 1998, p.17) whose support enables people to 'gain perspectives that could facilitate problem solving' (p.17). This person can inspire hope and confidence in people. The words of one patient and one partner illustrated this. The patient quoted on page 103 related how having an individual plan provided for him gave him confidence. He also stated:

> *In my particular case, if I have confidence in the individual then it has an enormously beneficial effect on me* (M1, 49-50).

The partner of another patient said:

:

> *She* (the cardiac education nurse) *makes you feel you're the only person at the time"* (M3P, 177).

Factors that contribute to successful cardiac rehabilitation include "ongoing counselling, support, evaluation and reinforcement" (Gulanick, 1998, p. 49) and a supportive environment is recommended by the Ottawa Charter (WHO, 1986) to encourage well-being rather than just promoting lifestyle changes. Cardiac educators are ideally placed to fulfil this role, but are presently constrained by the number of visits they can make to see patients and their families. Re-examining the role of cardiac educators also offers the potential to "strengthen community action" and "re-orient health services" (WHO, p.2), the very components of the Ottawa Charter recommended for health promotion. There are now programmes to educate nurses for this role (Gulanick, 1998) and also ones seeking to change the way of delivering cardiac education programmes with more focus on the community (Leighton, 1998; McSherry et al., 1999). An area where support is required for both patients and partners in the information chain is the early discharge period.

You just sort of box on

This theme showed how participants attempted to adjust to life after a heart attack and following discharge from hospital. This process was not helped when discharge information was not provided to GPs, sometimes for weeks after discharge, and communication between health professionals was lacking. Additionally, the lack of specific information, particularly relating to everyday activities increased the uncertainty for both patients and partners. The role of the cardiac educator bridges the gap in the educational process that can occur post-discharge and was mentioned in the literature review as well as being supported by the results of this study. In the literature, partners also identified this as a time when they most needed help (Coyne & Smith, 1991; Dickerson, 1998). In view of this, provision of more information here and less in hospital would seem logical. The studies mentioned above suggest ways of moving Phase 2 education into community settings rather than hospital.

An alternative role for the cardiac educator is described in a project in Southampton (UK) where practice nurses were directly involved in cardiac follow-up and discharge liaison was facilitated by the cardiac educator. When the project was discontinued, post discharge follow-up decreased mainly because of lack of discharge information (Wright, Jolly, Speller & Smith, 1999). Another programme initiated had district nurses visiting families post-discharge supported by the cardiac educator that resulted in an increase from 55% to 75% of patients going on to attend cardiac rehabilitation classes (Imich, 1997). This has relevance to the problems with discharge information reported in this study and could be another potential way forward, with the cardiac educators acting as facilitators between hospital and community. This would also be dependent on the GP supporting the initiative (Wright et al. 1999) and appropriate funding provided.

In the longer term, the process of coping and adjusting to life after an MI is reliant in part on patients and partners receiving information relevant to their needs (Keckeisen & Nyamathi, 1990). The literature on coping in Chapter 7 suggests that patients have different coping mechanisms, and that patients who are unable to identify causes and/or changes they can make in their lifestyle to improve their chances of not having another MI, are likely to experience problems. Once again, there is evidence here of the need for individual information programmes to facilitate the differing needs of people.

Thus if the cardiac rehabilitation programmes in New Zealand wish to achieve their aim of using all measure "to help cardiac patients achieve an active and satisfying life and to establish a basis for long term secondary prevention" (NHF, 1997, p.3) they need to provide the type of individual information and support post-discharge which should in turn empower people as suggested by the WHO (1997b), and give them confidence and hope. Re-organisation of the education programmes and more flexible delivery such as in community settings is one way forward (Leighton, 1998; McSherry et al., 1999).

There is no doubt that improvements have been made in cardiac rehabilitation, and this is born out by participants in this study who had previous experiences of when they received little or no information. It is interesting that at times, they now feel there is too much information to the extent that the effect is greatly reduced and does not always meet the needs of individuals. Apart from a commitment to relocate funding from secondary to primary care, and implement more flexible programmes, a very simple change which could be introduced would be to have the NHF booklet (Silverstone, 1997) provided as the core source of written information, from which all health professionals could work and other literature could be handed out on a need to know basis. The advantage of this booklet is that with the help of staff, patients and partners can write in their own goals and individualise the advice provided.

The impact of a patient's MI on partners requires further research. There appear to be several areas that could be improved and support programmes for partners as suggested by Norman (1997) might be a way forward. There may well be partners other than spouses who require support, particularly in these days of same sex relationships, and as represented by one couple in this study, where siblings live together.

IMPLICATIONS FOR NURSING

Two main issues arise for nursing from this study, the first is the need to provide nurses skilled at helping patients and partners, who can empower people to make lifestyle changes and are able to recognise factors affecting how people cope and work with patients and partners to facilitate this. This would involve educating nurses in coping strategies and also encouraging nurses to help patients with individual action plans (Scherck, 1992). The ability to develop the qualities to be a helpful person (Dickerson, 1998) would be beneficial to both patients and partners. Equipping nurses with these skills has been discussed on the previous pages, but also links into the topical and ongoing literature in Australasia relating to advanced nursing practice, at least one of these sources linking directly to cardiac education nurses (Pelletier et al., 2000).

The second relates more to how nurses, especially in acute care settings, meet the physical needs of patients and specifically women. As reported by Scherck (1992), nurses need only ask patients to unearth information which will "dispel misconceptions, support appropriate decisions and deal with a variety of aspects and hospitalisation that may have some positive influence on appraisals, use of coping strategies and recovery" (p.333). As well as asking, nurses need to listen and it appears that this does not always occur as illustrated by the women in this study seeking pain relief. Pain and distress are recognised stressors and likely to delay the recovery process if not reduced and nurses are not creating a supportive environment (WHO, 1997b) if they fail to address these issues.

LIMITATIONS OF THE STUDY

Limitations of this study include the sample size, particularly with regard to partners and female patients. The problems of conducting research within the timeframe of completing an academic degree mean that there is little room for delays. In this study, there was the initial problem with the method of recruitment discussed in Chapter 3 and requiring a return to the ethics committee to approve an alternative approach to participants. I feel that there is another issue in New Zealand which impacts both on recruitment numbers and types of patients volunteering to take part, and that is information sheets.

Information sheets

The recent history of New Zealand in relation to research has resulted in information sheets that are extensive and contain a lot of information participants are expected to read. With regard to this study, there is an issue that patients had already identified, that they had been overloaded with written information and may therefore have been put off taking part by having to read even more. These information sheets also exclude anyone who does not find reading easy or is illiterate. Three potential participants refused to take part having received the information sheet, and in at least two of the cases, I felt the amount and nature of reading contributed to this decision.

Following these experiences, I felt it necessary to stress during the first telephone call that the information sheet was very long and had a lot of information in it that I was required to give them in that first contact, but that would they please let me know if they had any queries. I also stressed the point that it was entirely their choice whether to proceed or not.

Although not excluded I received no Maori volunteers. I ended up with literate, white, middle class participants, exactly the group who might be expected to be having most of their information needs met by the cardiac rehabilitation programmes as they are presently run. New strategies may be needed in future to ensure a wider mix of participants take part in this sort of research. As a final limitation, I acknowledge that the findings may not be representative of cardiac rehabilitation programmes in all hospitals in New Zealand.

RECOMMENDATIONS FOR FURTHER RESEARCH

The following areas are identified as needing more research, particularly in New Zealand where specific data is lacking.

- The role of cardiac educators, and what makes an effective helpful person.
- The treatment of women suffering from a heart attack.
- Research that captures more diverse populations in terms of social and cultural background and includes more partners who are not wives.
- Comparison between traditional and participatory educational approaches in achieving the aims of cardiac rehabilitation.
- Studies concentrating on social outcomes of lifestyle changes for partners over which they have no control.

This small study provided strong evidence for a future role for nursing in cardiac rehabilitation which needs to be expanded and has the potential to affect world and government targets on IHD, while also making life after a heart attack much more bearable for both patients and partners. In relation to the title of this study, our aim should be that patients and partners can say, "they did explain everything, and I do remember", and the remembering would be knowledge relevant to their own specific needs.

SUMMARY OF THE STUDY

The information collected in this study provided four themes that covered the experience of a heart attack, how it differed for women, the provision of information and carrying on after a heart attack. Unlike much of the existing literature on experiencing a heart attack, which describes patients as denying that they are having a heart attack, the descriptions from participants in this study suggest that as the experience is generally outside their frame of reference, they genuinely do not recognise what is happening. This accounts for the delay in seeking help, which can result in patients not receiving the optimum medical treatment. In women, these delays are compounded by the inability of health professionals to recognise that a heart attack is occurring.

In relation to information and coping after a heart attack, this study showed that in spite of the wealth of information provided by written, visual and verbal means, participants were often left lacking information specific to their own physical, social and psychological needs. Education was usually delivered by a traditional model that restricts participation by individuals in the process. As receiving relevant information is an essential link to the coping and adjustment that takes place after a heart attack, this is an area of concern. The role of specific nurses as cardiac educators demonstrates how a participatory model of health education can meet this need. The provision of more of these nurses, along with a reconsideration of the cardiac rehabilitation programmes to better meet the aims of the NHF (1997) including the timing of when most of the education is provided is suggested.

APPENDIX A

Six Stage Treatment Plan

Because your heart has been damaged, it is important that you resume your activities ***gradually.*** This will assist the healing process. During your time in hospital, your nurse or doctor will make a daily assessment of your condition and when you should move to the next stage of your mobilisation programme. ***If you experience any chest discomfort, shortness of breath, dizziness or palpitations, tell the nursing staff immediately.***

Stage 1 *Date:*
Bed rest. (You may be wheeled to the toilet).

Stage 2 *Date:*
Up to shower and toilet. (You may require assistance).

Stage 3 *Date:*
Walk to shower and toilet. Walk in the corridor.

Stage 4 *Date:*
Walk in the corridor for increasing periods as you feel able. Wear street clothes if you wish.

Stage 5 *Date:*
Under nursing supervision, walk up one or two flights of stairs ***only.***

Stage 6

Taken from Silverstone (1997)

APPENDIX B

Massey University
COLLEGE OF HUMANITIES & SOCIAL SCIENCES

School of Health Sciences
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5668

LETTER OF INTRODUCTION

Information needs of patients and partners following hospitalization for a heart attack.

My name is Jenny Phillips, and this year I am completing my Master of Arts Degree by undertaking research into cardiac education programmes. My research supervisor is Professor J.Boddy, Head of the School of Health Sciences at Massey University. I am a nursing tutor at --- and am taking 2 years to complete this study while still continuing with my job.

I would like to invite you to consider participating in this research. I would also like some partners to take part if they wish to.
If you consent to the research, I would come and interview you for about half an hour and your partner separately for the same amount of time.
If your partner does not wish to take part, or you have no partner, this does not stop you from participating in the study.

If you wish to consider taking part in this research, please fill in the enclosed form and return in the Self-addressed envelope, or contact me at home on ----- and I will answer any questions and send you an information sheet. It is better to telephone in the evenings if you want to speak to me, otherwise if you leave a message, I will get back to you. Your participation is entirely voluntary, and complete confidentiality will be maintained.

If you have any questions regarding this research, you may contact Professor J.Boddy; School of Health Sciences, Massey University.

APPENDIX C

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REPLY SHEET

I am interested in taking part in the research study;

Information needs of patients and partners following hospitalization for a heart attack.

My spouse/ partner is also interested in being interviewed. YES/NO.

Name:

Address:

Telephone Number:

Best times to contact me:

APPENDIX D

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INFORMATION SHEET.

Information needs of patients and partners following hospitalization for a heart attack

Researcher; Jenny Phillips.

You are invited to take part in a study about the information you would have liked to receive following your partner's heart attack. This research is being completed as part of the requirements for a Master of Arts Degree.

The Heart Foundation are interested in knowing what information patients and their partners want following hospital admission for a heart attack. They also want to know what factors are likely to result in or hinder lifestyle changes. All patients who have had a heart attack and been admitted to ---cardiac wards over a 2 month period will be invited to take part. It is hoped to interview 15-20 people and at least half that number of partners. Not all patients will have partners. Interviews will be arranged in patients' homes, or at another venue of their choice.

The researcher is interested in getting the patient's (and in some cases, their partner's) viewpoint on what they would have liked to receive in the way of information during the period following a heart attack. Additionally, the researcher wants to know whether any lifestyle changes have been made since the heart attack. The interviewer (who is the researcher) will want to hear your own experiences and feelings, so the interview will not contain a lot of questions. Interviews will take about 45 minutes to an hour. Partners will be interviewed separately, for about the same time.

The interview will be taped. This makes it easier for the researcher to go over the information afterwards. The only other person who will hear the tape will be the transcriber and the researcher's supervisor. The transcriber types out the interviews so that all the information can be analyzed and the researcher can see whether several participants have identified similar needs. The transcriber also signs a form of confidentiality relating to the tapes. On completion of the research, you may request the tapes are returned to you, or they will be kept in a secure place for 5 years and then destroyed. Following the interview, the researcher will contact you once again by telephone to check that the key points she has identified were the ones you mentioned, and if necessary ask you to clarify any points raised. You will also be sent a summary of your interview to correct if you feel the information is not accurate. It is hoped that the interviews will start in October 1998 and be completed by December 1998.

Your participation is entirely voluntary and will have no effect on any future care for your partner. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your own or your partners future care.

You have the right at anytime during the research:

- To ask any question about the research
- To refuse to answer any question
- To ask the researcher to leave at any time
- To ask that the cassette recorder be turned off
- To examine any notes taken
- To discuss and amend any subsequent transcription
- To terminate the interview at any time
- To be informed of the results on completion of the research in 1999.

More information can be obtained from Prof.J.Boddy

If you have any queries or concerns about your rights as a participant, in this study, you may wish to contact the Health and Disability Services Consumer Advocate,

No material that would personally identify you will be used in any reports on this study. Your interviews will be allocated a number known only to the researcher and this will be kept locked away from the consent form with your name on. Computerized data will be stored in a secure file on a home computer.

It is hoped that the results of this study will be published in a professional nursing magazine and presented at a New Zealand conference in Wellington.
Please feel free to contact the researcher if you have any questions about this study.

Home phone number. ---If I am not there leave a message and I will get back to you.

The --- ethics committees have approved this project.

Thank you for your interest and taking the time to read this information

APPENDIX E

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CONSENT FORM.

Title: Information needs of patients and partners following hospitalization for a heart attack

Researcher: Jenny Phillips

I have read and understand the information sheet and have had the details of the study explained to me. I have had the opportunity to discuss this study. I understand that I may ask further questions at any time.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my continuing health care/my partners continuing health care. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

Information obtained will be used only for this research and publications or presentations arising from this research project.

I agree/do not agree to the interview being audiotaped.

I understand that I can request that the audiotape be turned off at any time during the interview.

I agree to participate in the study under the conditions set out in the information sheet.

Date.

Signature.

Name.

APPENDIX F

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Undertaking as to non-disclosure of information

Whereas, I

Currently residing at

Have agreed to transcribe tapes made during interviews conducted by Jenny Phillips, for the purposes of a research project. As part of the transcription process, I will hear names and other forms of identification of people.

I agree that I will not, at any time, directly or indirectly share or divulge any information concerning the identification of participants and/or identifiable institutions to which I have been given access.

I understand that only Jenny Phillips and Dr Julie Boddy, the research supervisor, will be allowed to access information on the tapes. The researcher, research supervisor and the particular research participants will have access to the transcriptions of the tapes.

I also understand that I will not at any time, either directly or indirectly divulge to any department, agency or institution information to which I have been given access.

Name:
Signed:
Witnessed by:
Name:
Designation of Witness:
Date:

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