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**Reframing Everydayness: A Grounded Theory Study of
Women's Perceptions of the Contribution of Cardiac
Rehabilitation to Their Recovery from a Heart Attack**

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ABSTRACT

Coronary heart disease (CHD) is a serious health issue for women but, in the past, women have been under-represented in research related to this condition. Instead, research using male populations has been used as a basis for the diagnosis and treatment of CHD in women. This has resulted in men and women being treated the same despite the presence of physiological and social differences. To ensure future diagnosis and treatment is based on appropriate research related to women and CHD. Grounded theory was used to explore women's perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack.

The constant comparative method of data analysis was used to develop categories from the data. Overall the experience of suffering a heart attack caused disruption to everyday life and functioning. This included interruption to activities and social roles and shock at having suffered a heart attack. Recovery was characterised by 'reframing' their lives based on the alterations caused by their heart attack experience. The women in this study attempted to return to their everyday roles and responsibilities through the basic social process of "regaining everydayness".

Most women did not recognise that they had received phase one cardiac rehabilitation, and although phase two cardiac rehabilitation met some of the education needs of the women in this study, it did not provide the support that all participants required. For some participants social needs were met by attending cardiac rehabilitation sessions. Phase two cardiac rehabilitation attendance was affected by transport, time, family and social issues, such as work commitments. Although some aspects of cardiac rehabilitation were beneficial for most participants, it did not appear to aid recovery for all of them.

DEDICATION

This thesis is dedicated to all of the women who participated in this research by telling their stories. It is also dedicated to the many New Zealand women who die annually from heart attacks.

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KEY

The following key will assist you with interpreting the transcript examples during the discussion of results:

(...)	Text removed.
(CR Nurse)	Cardiac rehabilitation nurse.
(bracketed words)	Words added by author to enhance meaning.
...	Pause.
1:	First interview.
2:	Second interview.
numbers-numbers	Line numbers of transcript, e.g. 296-299.
<i>Bold Italics</i>	Interviewer's speech.
<i>Italics</i>	Participants speech

Chapter 1

Introduction

Introduction

Heart disease is an important issue for all New Zealanders. According to the New Zealand Ministry of Health (MOH), Coronary Heart Disease (CHD) is the single leading cause of death for New Zealanders. In 1997, CHD accounted for 21% of female deaths and 25% of male deaths (MOH, 1999). In 1996 New Zealand women lost 25,526 years to premature mortality and 4296 years to disability as a result of CHD (Tobias, 2001). Despite the high death and disability rates, there is a lack of relevant research related to CHD in New Zealand women. As a result of this lack 'women and heart disease' is a current research priority for the National Heart Foundation of New Zealand (NHFNZ). One of the NHFNZ's specific areas of interest is to identify why women do not participate in formal cardiac rehabilitation programmes as often as men.

This chapter provides an outline of the aim, research questions and objectives of this study. Included is a discussion of CHD and heart attack incidence, cause, treatment and recovery. The definitions and goals of cardiac rehabilitation both from New Zealand and overseas are also provided. Prior to the commencement of this study a review of the relevant literature related to women and cardiac rehabilitation was performed. This chapter also provides a summary of that literature focusing on gender issues, attendance and referral, experience, exercise, role expectations and education needs.

Aim, Research Question and Objectives

A heart attack is a serious condition that may result in death or disability, due to damaged myocardium (heart muscle). Damage to myocardium often results in decreased ability to cope with exercise and stress, and as a result of this, the recovery process can be long (Ades, 1999). Cardiac rehabilitation has been shown to improve recovery for heart attack sufferers (Petrie & Weinman, 1997).

Although there has been research into cardiac rehabilitation much of that research has focused on exercise tolerance (Cannistra, Balady, O'Malley, Weiner & Ryan, 1992), participation in exercise programmes (Balady, Jette, Scheer & Downing, 1996; Cannistra et al., 1992; Lavie & Milani, 1995; Moore, Ruland, Pashkow, & Blackburn, 1998), risk factors, referral, attendance (Halm, Penque, Doll & Beahrs, 1999), and usefulness of programme content (Castelein & Kerr, 1995; Filip, McGillen & Mosca, 1999; Murray, 1989).

The vast majority of past research is quantitative in nature and performed using mostly male subjects (Boogaard, 1984; Brezinka & Kittel, 1996; Wenger & Hellerstein, 1992). It has been suggested that women have different symptoms and present in a different manner than men when having an acute cardiac event (Halm & Penque, 1999). It is therefore possible that women also cope with symptoms and illness in different ways. Women have different roles and responsibilities to men within our society, so their needs in relation to cardiac rehabilitation may be different to those identified from research on male populations. I could find very little research that looked at how women experienced cardiac rehabilitation or whether they felt they benefited from it. I wanted to know if low attendance rates are related to how women think cardiac rehabilitation programmes contribute to their recovery. Therefore, the research question for this study was:

“What are women’s perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack?”

The objectives of this study were to:

- Identify women’s perceptions of cardiac rehabilitation after a heart attack.
- Identify the effect that they perceive phase one and phase two cardiac rehabilitation has had on their recovery within three years of suffering a heart attack.
- Identify why some women chose not to attend or complete phase two cardiac rehabilitation programmes.

Coronary Heart Disease

CHD, also called ischaemic heart disease (IHD) refers to any cardiac syndrome or collection of symptoms, caused by a blockage of blood supply to the coronary arteries (Donker, 2000). CHD is a condition in which an imbalance exists between myocardial oxygen demand and supply. This imbalance occurs for a variety of different reasons but is most often due to coronary artery disease (CAD). When the supply of oxygen to the myocardium is inadequate, varying degrees of ischaemia occur (Cunningham, Bene, & Vaughn, 2000).

There are two types of myocardial ischaemia. The first is supply ischaemia, which results from functional or structural abnormalities in the coronary arteries leading to decreased blood flow. The second is demand ischaemia, which results from an increase in heart rate, contractility or heart size. Each type of myocardial ischaemia is reversible, however if the ischaemia is prolonged or severe it can lead to irreversible injury (Cunningham et al., 2000).

CHD is caused by the development of thick plaques (atheroma) on the inner walls of the blood vessels (Burke, 1992; Smeltzer & Bare, 2000). These atherosclerotic plaques protrude into the lumen of the blood vessel causing narrowing and obstructing blood flow (Smeltzer & Bare). The atheroma has a lipid core that can rupture and haemorrhage into the plaque. When a plaque ruptures a clot is formed to seal the rupture. This clot, in turn, further narrows or even occludes that blood vessel (Cummins, 1997). Immediately after a coronary artery becomes occluded the majority of the blood flow through that artery ceases beyond that point, resulting in myocardial ischaemia. Within a few hours of little or no blood supply an area of myocardial necrosis (tissue death) occurs (Burke; Gyton & Hall, 1996).

Mortality from CHD has been decreasing in New Zealand over the last 20 years. In 1997 the mortality rate from CHD was 97/100,000, which was reported to be the lowest rate since 1980 (MOH, 1999). Despite this, CHD is one of the leading causes of mortality in both men and women in New Zealand and many other developed countries (Cummins, 1997; MOH). According to the New Zealand Health Information Service (NZHIS), 3463

women died in 1997 from some form of heart disease (NZHIS, 2000). In 1998 1407 New Zealand women died from heart attack alone (NZHIS, 1999).

Heart Attack / Myocardial Infarction

Suffering a heart attack may be the first sign that a person has CHD. Published accounts suggest that people most often present with acute chest pain, which may radiate down one or both arms, into the jaw and neck or into the back (Cunningham et al., 2000). Pain may be accompanied by shortness of breath, nausea and vomiting. The myocardium, or heart muscle, is supplied with blood by coronary arteries that branch off from the aorta (Hubbard & Mechan, 1997; Watson, 2000). An acute myocardial infarction (AMI), or heart attack as it is commonly called, occurs when there is a disturbance in the blood supply to the myocardium. This can be caused by the formation of a thrombus (clot) or by spasm of the vessel wall (Gyton & Hall, 1996). The severity of the condition depends on where the blockage has occurred and how well the body is able to deal with the crisis (Hubbard & Mechan).

A heart attack can be divided into four phases (Cunningham et al., 2000). Phase one, ischaemic insult, lasts for about four hours after the blood flow ceases. Phase two, the coagulation necrosis phase, lasts from approximately four to 48 hours after the initial blockage. Phase three, the healing phase, lasts from approximately 48 hours to two weeks. The final phase, the scarring phase, begins approximately one week after infarction and can last several months after the initial blockage (Cunningham et. al). The time taken for healing of the myocardium to occur varies between individuals but usually takes six to eight weeks (Silverstone, 2000).

As a result of a heart attack the effectiveness of the myocardium to pump blood around the body may be reduced (Hubbard & Mechan, 1997). Sometimes a heart that has recovered from a myocardial infarction is able to pump almost as effectively as it did originally. However more often the pumping capability of the heart is reduced, potentially resulting in an alteration in self-care ability (Gyton & Hall, 1996). For the purpose of this thesis the term heart attack will be used instead of AMI as this is the terminology used by the women in this study.

Management

When people are initially admitted to hospital with a suspected heart attack they are asked to remain on bed rest while blood tests and electrocardiographs (ECGs) are done to confirm the diagnosis. Once a heart attack has been diagnosed they are then put on a mobilisation programme (appendix 1), where their activity is limited and then increased gradually each day (a summary is provided in table 1).

Table 1: Summary of Mobilisation Programme

Stage 1	Bed rest.
Stage 2	Up to shower and toilet.
Stage 3	Walk to shower or toilet. Walk in the corridor.
Stage 4	Walk in the corridor for increasing periods as able. May wear street clothes.
Stage 5	Under nursing supervision, walk up one or two flights of stairs only.
Stage 6	Discharge home.

Each stage of this programme is generally followed for a period of 24 hours. People progress through the stages with gradual increases in activity leading eventually to discharge from hospital. The aim of the initial management for a heart attack is to reduce or limit the amount of damage to the myocardium by increasing blood flow and oxygen supply to the heart muscle, reducing the heart muscle's demand for oxygen, detecting and managing any complications, and assessing risk for further heart problems. This is achieved through encouraging rest, cardiac monitoring, close observation and administration of oxygen, pain relief, and thrombolytic therapy. Thrombolytic therapy breaks down the clot causing the blockage in the coronary artery allowing blood flow to return to the affected heart muscle (Cunningham et al., 2000).

Once the acute phase of the illness is over, management aims include preventing further complications and providing education. Patients are then referred for cardiac rehabilitation, which is aimed at improving the patient's quality of life through the reduction of risk factors for heart disease. Cardiac rehabilitation is usually started at the time of an acute cardiac event such as a heart attack (Ritchie & Myers, 2000).

Illness and Recovery

Interpretation of the signs and symptoms related to illness may affect the timing and type of treatment sought. How illness is viewed may also affect the individual's perception of recovery. To examine illness and recovery it is necessary to have a clear understanding of the meanings of the terms. Illness can be viewed from the biomedical perspective or the viewpoint of individual experience. The biomedical perspective views illness as "an abnormal process in which aspects of the social, physical, emotional, or intellectual function of a person are diminished or impaired, compared with that person's previous condition (Anderson, Anderson, & Glanze, 1998, p. 814). According to Benner and Wrubel (1989, p.8) illness is "the human experience of loss or dysfunction whereas disease is the manifestation of aberration at a cellular, tissue or organ level". This definition differentiates how the individual experiences illness from what is happening physiologically within their body. Illness behaviour refers to the different ways that individuals monitor and respond to internal states, make sense of symptoms and take actions (Mechanic, 1995).

Unlike illness, recovery is a term that has been used to describe different processes. It has been used synonymously with terms such as healing and rehabilitation. Recovery has been described as the return or restoration to a former, usual or correct state of health (Brown, 1993). This is not a particularly useful definition because it is unclear what is meant by a 'correct state of health'. According to Lawler (1991) recovery is about becoming independent and regaining control over the care and functions of one's body. Recovery is further defined by the Mental Health Commission as the ability to live well or the absence of mental illness, or whatever the person names their experience (O'Hagan, 2000). This suggests that the experience of being well or ill is different for everyone. Although there are clear definitions for recovery it was not clear before this study started what recovery would mean to the participants. However, it is necessary to have some understanding of the definitions and meaning of illness and recovery before examining the perception of effectiveness of cardiac rehabilitation programmes.

Cardiac Rehabilitation

There are many definitions provided for cardiac rehabilitation (Comoss, Burke & Swails, 1979; Mitchell, Muggli & Sato, 1999; Noy, 1998). Comoss et al. (p.2) define cardiac

rehabilitation as “the process of actively assisting the known cardiac patient to achieve and maintain his (sic) optimal state of health”. Although this definition fails to describe the components of cardiac rehabilitation programmes it does identify the goal. These authors stress that rehabilitation is not something that is done to the patient by the health professional, but is something that is accomplished by the patients themselves. This implies that cardiac rehabilitation involves the health professional and patient working together to identify problems and plan solutions.

New Zealand cardiac rehabilitation programmes are based on the guidelines and definitions provided by the NHFNZ. The NHFNZ guidelines are, in turn, based on the World Health Organisation (WHO) definitions and aims. Table 2 shows the definitions of cardiac rehabilitation provided by both of these organisations. Although the statements from the NHFNZ incorporate some of the aspects highlighted by the WHO, they fail to highlight the need to educate every health care worker and the general public about the benefits that can be gained from cardiac rehabilitation (WHO, 1993).

Cardiac rehabilitation, both in New Zealand and overseas, has three recognized phases; phase one, the inpatient phase; phase two, the outpatient phase (up to 12 weeks post event); and phase three, the maintenance phase (New Zealand Guidelines Group, 2002b; Parks, Allison, Doughty, Cunningham & Ellis, 2000). Inpatient cardiac rehabilitation focuses on gradual mobilization, the resumption of activities of daily living, education, discussion and support including counselling if required, as well as discharge planning. Outpatient cardiac rehabilitation includes a light to moderate exercise regime and further education, discussion and support (Australian Heart Foundation, 2000). Patients are generally encouraged by hospital-based nurses and cardiac rehabilitation nurses to attend phase two cardiac rehabilitation after they are discharged from hospital.

Topics covered in cardiac rehabilitation programmes include: the basic anatomy and physiology of the heart; the effects of heart disease; the healing process; risk factor modification; the resumption of physical, sexual and activities of daily living; psychosocial issues; management of symptoms, and investigations; and individual assessment and referral to other health professionals as required (AHF, 2000; NHFNZ,

2000). Different terminology is used to describe programme components in different countries, which makes comparison difficult.

Table 2: WHO and NHFNZ Cardiac Rehabilitation Definitions and Aims.

<p>World Health Organisation</p>	<p>The sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible physical, mental and social conditions, so that they may, by their own efforts, preserve or resume when lost, as normal a place as possible in the community (WHO, 1993, p. 1).</p> <ul style="list-style-type: none"> • Cardiac rehabilitation is an essential part of care that should be available to <i>all</i> cardiac patients. • The goals of cardiac rehabilitation are to alleviate or lessen activity related symptoms, improve functional capacity, reduce invalidism and enable return to a useful and satisfying role within society (WHO, p. 1). • Cardiac rehabilitation should be provided by any trained health professional caring for cardiac patients. • Rehabilitation programmes should be integrated into the existing health care system (WHO, p. 99).
<p>National Heart Foundation of New Zealand</p>	<p>Cardiac rehabilitation is the coordinated sum of interventions required to ensure the best physical, psychological and social conditions so that patients with chronic or post acute cardiovascular disease may, by their own efforts, preserve or resume optimal functioning in society and, through improved health behaviours, slow or reverse the progression of disease (NZGG, 2002b, p. 5).</p> <ul style="list-style-type: none"> • Rehabilitation of patients who have been treated for cardiac disorders is a necessary aspect of medical care to which all patients with cardiac disorders are entitled. • Cardiac rehabilitation should be an integral component of the long term comprehensive care of patients. • Cardiac rehabilitation programmes or services should be available to all patients with cardiovascular disease. • Rehabilitation services should be provided by any trained health professional caring for cardiac patients, since no sophisticated equipment or facilities are required. • Both patients and their families should participate (NHFNZ, 2000, p. 6)

Cardiac rehabilitation can be described as a dynamic process that assists individuals who have survived a heart attack or other cardiac event to achieve the best level of functioning possible (Mitchell et al., 1999). Cardiac rehabilitation should begin at the time diagnosis of CHD is made (Comoss et al., 1979), which is usually as the result of an acute event such as a heart attack. Cardiac rehabilitation programmes are aimed at helping individuals to adjust to their illness, limit or reverse the disease, modify risk factors for future cardiac illness, improve return to occupational and social functioning, and reduce the risk of re-infarction or sudden death (Dinnes, 1998; Mitchell et al.; Petrie & Weinman, 1997; Wenger et al., 1995).

Wenger et al. (1995) suggests that cardiac rehabilitation is characterised by long-term services that are comprehensive and involve medical evaluation, prescribed exercise, health education to encourage modification of cardiac risk factors, counselling and interventions to modify behaviour. Wenger et al. do not explain what they mean by long-term, however this may be because cardiac rehabilitation programmes last for varying amounts of time. The guidelines provided by the Australian Cardiac Rehabilitation Association suggest that phase two cardiac rehabilitation should last for four to twelve weeks (AHF, 2000).

Cardiac rehabilitation has been shown to benefit patients with a wide range of cardiac conditions including heart attacks. Research studies report an increase in functional capacity (Adams et al., 1999; Cannistra et al., 1992; Lavie & Milani, 2000) and a decrease in mortality (Naughton, Dorn, & Imamura, 2000; Oldridge et al., 1991) for both men and women after cardiac rehabilitation. Research shows that depression is a common result of CHD (Ades, Maloney, Savage & Carhart, 1999; Lavie, Milani, Cassidy, & Gilliland, 1999; Low, 1993), and has been found to be more severe in women (Ades et al.). Cardiac rehabilitation has been linked to decreased levels of anxiety and depression and to improvement in general health, self-esteem (Ades, 1999; Conn, Taylor, & Casey, 1992; Petrie & Weinman, 1997), shorter hospital stays, better emotional and spiritual recovery and greater compliance with lifestyle recommendations aimed at reducing cardiac risk factors (Guzzetta & Dossey, 1992). Although much of the available research was conducted outside of New Zealand, the findings of these research studies are still relevant due to similarities in dietary habits, risk factors for CHD, and rates of cardiac illness.

Lavie et al. (1999) investigated the effects of depression in women with CHD and the effects of cardiac rehabilitation and exercise training on this group. They found that women with depression had marked improvements in behavioural characteristics, depression scores, and overall quality of life. Cardiac rehabilitation programmes including exercise have shown improvement in participant's aerobic fitness and muscle strength (Ades et al., 1999), which also contributes to the prevention and treatment of coronary disability (Ades et al.), and a decrease in mortality (Fletcher, 1998; Oldridge et al., 1998).

Cardiac rehabilitation programmes appear to vary widely in their focus and composition around the world and even within New Zealand. The focus of American programmes appears, from the literature, to be largely on exercise (Ades et al., 1999; Balady et al., 1996; Bruce, Frederick, Bruce, & Fisher, 1976). The American Heart Association states Phase two programmes also provide information on smoking cessation, nutrition and stress management training (American Heart Association, 1998). Although the format and composition of cardiac rehabilitation programmes varies between countries, the aims of cardiac rehabilitation remain very similar.

Gender Issues

It is not only important to understand what cardiac rehabilitation is, it is also necessary to have an understanding of the different groups of people who may attend cardiac rehabilitation programmes. CHD has traditionally been viewed as a disease that largely affects males and therefore was not recognised as a serious health problem for women. Although it is now viewed as a problem for women, CHD is often not diagnosed as promptly and women are not treated as aggressively as men (Arnstein, Buselli & Rankin, 1996; Jensen & King, 1997). Women generally suffer from CHD ten to fifteen years later than men, and experience their first myocardial infarction 20 years later than men (Giardina, 2000; Halm et al., 1999; Jensen & King). Lockyer and Bury (2002) suggest that it is not only younger women but all women who are seen as being less at risk for developing CHD than men of similar ages, and as a result of this, the issue of women and CHD has been neglected both by feminists and the medical profession (Lockyer & Bury).

Cardiac rehabilitation is an area of growing importance for women due to the increase in the number of women suffering from cardiac illness. Over the last ten years there has been

an increasing number of research studies looking at gender differences both in cardiac rehabilitation participation and the benefits sustained (Ades et al., 1999; Blackburn et al., 2000; Conn, Taylor, & Abele, 1991; Lieberman, Meana, & Stewart, 1998; Rankin, 1990; Romeo-Ashton & Saccucci, 1996; Schuster & Waldron, 1991).

It is apparent that women benefit as much as men from cardiac rehabilitation (Ades, Waldman, Polk & Coflesky, 1992; Cannistra et al., 1992; Lavie & Milani, 1995). Ades, Waldman & Polk et al. examined the exercise capacity of older female and male patients before and after a 12-week supervised aerobic training programme, and found that the peak aerobic capacity and maximal oxygen consumption of women improved significantly and at similar rates to that of men. In her study about the effect of gender on short-term recovery from cardiac surgery, King (2000) reported that women had a greater improvement in functional capacity than men. However, these findings also indicated that neither gender nor age consistently predicted the degree of recovery (King).

Attendance and Referral

Women's attendance at cardiac rehabilitation programmes has been documented to be lower than that of men (Halm et al., 1999; Wallwork, 1996). Parks et al. (2000) performed an audit of the phase two cardiac rehabilitation programme at Auckland Hospital and found that women were less likely to attend than men, with 36% of eligible women attending in comparison to 49% of men. A Minneapolis study found that 22% of women there attended cardiac rehabilitation in comparison to 41% of men (Everson, Rosamond & Luepker, 1998).

It is also evident from overseas research that women may not be referred for cardiac rehabilitation as readily as men (Cochrane, 1992). Ades, Waldman & Polk et al. (1992) found that physicians in Vermont recommended that older men participate in cardiac rehabilitation more often than older women despite both groups having similar clinical profiles. Everson et al. (1998) also found that women on the Minnesota Heart Survey Registry were referred for cardiac rehabilitation less often than men. An American study by Halm et al. (1999) of men and women found that 66% of men received referral for phase two cardiac rehabilitation in comparison to 48% of women. However research that

investigated patient characteristics related to referral to cardiac rehabilitation did not identify gender as a predictor of referral (Burns, Camaione, Froman & Clark, 1998).

A Canadian Study by Lieberman et al. (1998) examined whether gender was a factor that influenced cardiac rehabilitation participation. The results showed that both men and women ranked the recommendation of their physician as the most important factor influencing their participation. For women the influence of adult children was also important, whereas for men the influence of their spouse was important. This indicates that men and women rely on different support networks for decision-making related to cardiac rehabilitation attendance.

Women are perceived as being less motivated to attend cardiac rehabilitation programmes than men, especially programmes containing vigorous exercise (Blackburn et al., 2000; Wallwork, 1996). Halm et al. (1999) found that women provided multiple reasons for not participating in phase two cardiac rehabilitation including issues related to transport, insurance barriers, medical problems, and admission to a transitional care unit. Women have been found to have a higher degree of psychosocial impairment and a lower level of physical functioning on admission to a cardiac rehabilitation programme than men (Brezinka, Dusseldorp & Maes, 1998). Brezinka et al. suggest that this might partly explain the reported lower adherence and higher dropout rates of women in cardiac rehabilitation programmes.

Jette and Downing (1994) investigated the health status of individuals on entry to a cardiac rehabilitation programme. Their findings suggest that participants were most limited in their performance of life roles by physical problems. Gender was not found to be statistically significant (Jette & Downing). However because women are often older and have more existing health problems this could be an important finding. Schuster and Waldron (1991) found that upon enrolment in Ohio cardiac rehabilitation programmes women were significantly more anxious, less efficacious, less able to tolerate physical activity, and more likely to have an increased dropout rate than men. Implications of this include the importance of recognizing gender related differences and planning interventions to meet the individual's needs (Schuster & Waldron).

Moore and Kramer (1996) suggest that women are more likely to participate in cardiac rehabilitation programs that meet their needs. To achieve this however we need to understand what these needs are and what is currently available. Blackburn et al. (2000) compared patients who participated in the Cleveland Clinic Foundation hospital-based cardiac rehabilitation programme to patients who did not. They found a higher number of women participated in community-based programmes than in the Cleveland Clinic Foundation hospital-based programme. Wallwork's (1996) study of women concluded that the favourable up-take of the programme by women aged 65 years or under, who attended cardiac rehabilitation after being admitted to hospital with a heart attack, was due to the home visiting aspects of the programme and the relationships that subsequently developed between the patients and cardiac rehabilitation staff. Halm et al. (1999) identified that women were less likely to attend the cardiac rehabilitation programme at a large mid-western American hospital than men but did not identify if any community-based programmes were available.

Experience of Recovery After a Heart Attack

Researchers have investigated different aspects of women's experience with heart attacks, including women's experience of being the spouse of a heart attack sufferer (Arefjord, Hallaraker & Havik, 1998; Daly et al., 1998; O'Farrell, Murray & Hotz, 2000). Arefjord, Hallaraker, Havik and Maeland (2002) investigated the 'lay' illness understanding and the attribution of blame of women whose spouses had suffered a heart attack. Their findings indicate that women do not blame themselves but do blame their spouses for not taking action to prevent a heart attack.

Researchers have also explored women's experience of recovery after a heart attack. Jackson et al. (2000) used an exploratory descriptive study to explore the recovery experiences of a group of Australian women recently discharged from hospital following a heart attack. They found that recovery was a complex process characterised by feelings of fear and uncertainty, which changed over time to become feelings of confidence about the future. Fleury, Kimbrell and Kruszewski (1995) also investigated women's experience of recovery after a heart attack. They identified healing, as the basic social process, and explained how women struggled to create new health patterns out of the uncertainty of their acute cardiac event. Fleury et al. suggest that for cardiac rehabilitation to be an

effective strategy for improving the recovery and quality of life of women who have suffered an acute myocardial infarction it is necessary to have an understanding of women's experience of cardiac rehabilitation. This would enable the development of rehabilitative strategies that enhance the health of women.

Medich, Stuart and Chase (1997) provide a case study of one woman's experience after being diagnosed with CAD and participating in cardiac rehabilitation. They found that healing occurred through a process of integration in which the experience of CAD was incorporated into a "meaningful personal perspective" (p. 68). Jairath (1999) investigated how people who have experienced a heart attack communicate the meaning of their experience. Jairath found that meaning is conveyed through the use of metaphorical language. Metaphors focused mainly on the symptoms experienced by the individual.

Exercise

Exercise is an important aspect of recovery from a heart attack for both men and women. Research examining women's adherence to exercise regimes after an acute cardiac event indicated that the group of American women studied exercised below the recommended guidelines of the American Heart Association, with seventy-five percent exercising less than three times per week (Moore et al., 1998). It is interesting to note that in this study approximately one third of participants recorded all types of physical activity in their diary, including "picking up shells off the beach, child care and preparing dinner" (Moore et al., p. 321). This may indicate that there is a difference in what women perceive as exercise.

In New Zealand it has been recognised that to exercise participants do not have to take up a sport or participate in a group exercise activity. The Hillary Commission's 'Push Play' programme was launched in 1999 to encourage New Zealanders to participate in 30 minutes of 'physical activity' each day. Physical activity in this case includes anything that increases pulse rate and causes a slight sweat (Hillary Commission, 2000). The exercise recorded by women in the study by Moore et al. (1998) may be more accurately categorised as physical activity than defined as exercise.

Role Expectations

Gender role expectations of both patients and society have been shown to affect experience of and recovery from illness. Gender roles are socially constructed sets of behaviours that are considered appropriate for a particular gender (Beilharz & Hogan, 2002; Kornblum & Smith, 2000). Kornblum and Smith suggest that the unequal treatment of women in relation to men can be directly related to gender roles. More women are in paid employment now than in the past, and combined with this these women often attempt to maintain family and social roles (Schaefer & Lamm, 1998). A research study investigating the experiences of younger, pre-menopausal women after diagnosis of CAD discovered themes related to risk factors, initial symptoms, and decision to seek treatment, return to work, activity and coping. The results indicated that younger women were not expecting to suffer from CAD and thought their age and gender would provide protection from cardiac problems (LaCharity, 1999).

Hamilton and Seidman (1993) examined recovery from a heart attack in relation to return to work issues, participation in cardiac rehabilitation and sexual activity. Findings showed that within four weeks 75% of women had returned to household duties compared with one third of men. Results also indicated that women received less counselling than men, which may also affect their recovery. King, Humen, Smith, Phan and Teo's (2001) Canadian study of the relationships between demographic factors, specific psychological factors and cardiac rehabilitation attendance discovered that women reported less social support but showed a greater improvement in health maintenance self-efficacy expectation than men. However, this did not appear to affect attendance at the associated cardiac rehabilitation programme.

Education Needs

There is a growing awareness of the importance of having cardiac rehabilitation programmes that meet the learning needs of both men and women. Ashton (1997) set out to see how American men and women rated the importance of learning needs related to information about heart disease. Results indicated that the men and women participating in this study had different learning priorities. For example, women rated learning about medications as most important whereas men rated risk factor education. Ashton also found

that a higher percentage of women preferred to receive information from the physician and a higher percentage of men preferred gaining information from the nurse.

It has been suggested that recovery after a cardiac event does not proceed in the same way for every participant, and therefore an individual's needs should be assessed prior to attending rehabilitation programs (Lukkarinen, 1999). Individualized teaching plans that may include gender specific information would be an important step in promoting behavioural change if it is required (Ashton, 1997; Goodman, 1997; Halm et al., 1999; Noy, 1998). These individualised plans should be formulated to meet the needs of the patient, and the family should be included in the planning process (Dinnes, 1998; Miller, McMahon, Garrett & Ringel, 1989).

There are a variety of both research and non-research articles that discuss women's needs in relation to cardiac rehabilitation. These authors stress the need for research to increase understanding of women's experiences of cardiovascular disease (Fleury & Cameron-Go, 1997; Parchert & Creason, 1989); perceptions of symptoms and illness (McSweeney, 1998); learning needs (Boogaard, 1984; Romeo-Ashton & Saccucci, 1996); stress related to illness (Arnold, 1997); risk factor modification (Fleury & Cameron-Go); physical and psychosocial recovery in women (Fleury et al., 1995; Parchert & Creason).

As a result much of the research that has guided the development of cardiac rehabilitation programs has been based on an understanding of the process of rehabilitation in men (Boogaard, 1984; Konstam & Houser, 1994). It is apparent however that more researchers are focusing on studies that examine women's responses to CHD and the care and treatment they receive. For example research by Fleury et al. (1995) explores women's recovery from an acute cardiac event.

In the past women have perceived the greatest threat to their health to be cancer (Halm & Penque, 1999). Health statistics both in New Zealand (MOH, 1999) and the United States of America indicate that this is not the case (Halm & Penque). Not only are women suffering from CHD at high rates but they experience more complications and have a higher mortality rate post myocardial infarction than men (Cochrane, 1992; Giardina, 2000; Hamilton & Seidman, 1993).

Although much research has been undertaken into various aspects of cardiac rehabilitation, there is still a need for research which attempts to gain understanding of women's experiences of cardiovascular disease (Fleury & Cameron-Go, 1997); factors that effect the individual's decisions about cardiac rehabilitation attendance (Conn et al., 1992; Murdaugh, 1990); and research that seeks to identify specific problems encountered by women with heart disease to enable cardiac rehabilitation for women to be improved (Parchert & Creason, 1989; Romeo-Ashton & Saccucci, 1996). Nurses and other health professionals have a responsibility to help those who survive myocardial infarction to regain the quality of life they had previously or to attain the best quality of life they possibly can. A programme such as cardiac rehabilitation is one way that this may be achieved (Hijeck, 1984). To achieve an improvement in the recovery of women who have suffered a heart attack it is necessary to establish what their needs are and provide education programmes that meet these needs.

Cardiac Rehabilitation in New Zealand

When I first began working as a registered nurse in the area of cardiovascular nursing in the late 1980s, cardiac rehabilitation was offered on an inpatient basis only. The programme consisted mainly of individual education on risk factor modification, exercise, lifestyle modification and dietary information, along with some group discussion and health education videos. Nurses oversaw most of the cardiac rehabilitation programme with assistance from physiotherapists and dieticians.

In the early 1990s more formal cardiac rehabilitation programmes were set up around New Zealand to further meet the needs of people who had suffered a heart attack. Nurses were employed to provide the main education and support for these programmes. Their role was to see the client while they were in hospital in order to provide information, visit them when they were discharged home to give further information and ensure they were coping with being at home, and organize the local cardiac rehabilitation programme timetable and meetings. These programmes were set up to meet the 'minimum standards' set down by the NHFNZ (NHFNZ, 1995).

In New Zealand Phase two cardiac rehabilitation programmes run from between four to ten weeks depending on the hospital running the programme (NHFNZ, 2000). Programmes may be run on hospital grounds or at community based sites. Patients are invited to attend and given information sheets outlining dates, times and topics covered. Programme content usually includes education on self-management, nutrition, exercise, stress management and risk factor reduction. However, the actual content varies between programmes (NHFNZ).

According to the NHFNZ (2000, p.7) the aims of cardiac rehabilitation are to:

- Maximise physical, psychological and social recovery/functioning so that patients can achieve a lifestyle that is as productive and personally satisfying as possible.
- Encourage the adoption of a lifestyle that limits the progression of heart disease and minimises the risk of further cardiac events; assist patients to become physically active at a level which is compatible with the functional capacity of their heart and circulation;
- Promote self-responsibility in patients and encourage them to use appropriate health and community services.

The aims of cardiac rehabilitation in New Zealand are similar to those of the American definitions although the terminology is often different.

Cardiac rehabilitation services are provided free of charge to all New Zealanders who require them. All main centres within New Zealand provide cardiac rehabilitation programmes. Cardiac rehabilitation nurses within New Zealand are employed by district health boards (DHBs) and generally based in public hospitals. Cardiac rehabilitation is funded through the purchase of cardiac education and management purchase units (NZGG, 2002b). Phase one cardiac rehabilitation is carried out by nurses working in acute clinical settings such as coronary care units and post coronary wards. Cardiac rehabilitation nurses also visit people prior to discharge from hospital and may also visit them at home. Phase two cardiac rehabilitation programmes are organised by cardiac rehabilitation nurses, and sessions are taught by a variety of different health professionals, including dietitians, physiotherapists and doctors.

For health professionals to be able to provide cardiac rehabilitation programs that assist women recovering from a heart attack, it is important to identify what women's needs are. How women experience and perceive cardiac rehabilitation is the first step to gaining this understanding. Grounded theory methodology was used to investigate women's perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack. By gaining an understanding of how cardiac rehabilitation contributes to women's recovery, it was hoped that insight would be gained into whether or not cardiac rehabilitation, in its current form, meets the needs of women.

Summary and Conclusion

This chapter has provided a brief overview of the literature and issues surrounding CHD and cardiac rehabilitation. Although the incidence of CHD is decreasing in New Zealand it is still a major health issue for both men and women. Cardiac rehabilitation programmes have been shown to aid recovery from a heart attack and provide necessary information about modifiable risk factors so those at risk can act to reduce that risk as much as possible. However despite this women's referral and attendance at cardiac rehabilitation programmes is significantly lower than that of men. Although there has been a significant amount of research examining cardiac rehabilitation most focuses on men and is quantitative in nature.

It is important that cardiac rehabilitation programmes be available to all people who suffer from CHD. Issues of appropriateness and access need to be addressed to ensure that those who need this service are able to access it and that the service provides the information and support that each individual requires. The following chapter details the research method used for this study.

Chapter Two

Research Design and Method

Introduction

Qualitative research provides a way of looking at human experience, allowing the researcher to look at a problem or issue from an emic perspective, the perspective of the participant (Field & Morse, 1985). Qualitative research methods can help to reveal the nature of people's perceptions, experiences and actions (Glaser, 1992). Grounded theory has been used in this study to investigate women's perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack. This chapter discusses the theoretical underpinnings of grounded theory and how it was used in this study.

Theoretical Perspective

Grounded theory originated from the social science tradition of symbolic interaction founded in the disciplines of psychology and sociology (Chenitz & Swanson, 1986). According to Schreiber and Stern (2001, p. 178) symbolic interactionism is "a theoretical perspective that illuminates the relationship between individuals and society as mediated by symbolic communication". In this way symbols are used to enable communication allowing the development of shared meanings. Crotty (1998, p. 8) suggests that "symbolic interactionism is all about those basic social interactions whereby we enter into the perceptions, attitudes and values of a community, becoming a person in the process". Symbolic interactionism embodies the belief that individuals bring their own definitions, meanings and interpretations to social interactions (Glaser & Strauss, 1967). This implies that meaning in a particular situation is continuously modified by the individual's experiences of the world (Chenitz & Swanson).

According to Blumer (1969) symbolic interactionism has three basic premises. The first is that “human beings act towards things on the basis of the meanings that the things have for them”; the second is that “the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows”; and the third is that “these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters” (Blumer, p. 2). The theoretical perspective provided by symbolic interactionism allows the world to be viewed in a way that focuses on humans and their social interactions within society.

How we view the world is dependent on the experiences we have. Blumer (1969) proposes that the meanings we have for things are formed within the context of our social interactions and derived by the individual as a result of that interaction. He also suggests that the use of meaning by an individual about his or her action involves an interpretive process rather than being solely an application of derived meaning. Social interactionism recognises that social interaction is important because it is a process which “forms human conduct” rather than being just a “means or setting” for the expression of human conduct (Blumer, p. 8). In order to gain an understanding of human conduct it is necessary to examine human behaviour and the underlying meaning that motivates that behaviour (Schreiber & Stern, 2001). Schreiber and Stern suggest that it is this application of symbolic interactionism that is addressed through the sociologically based research method of grounded theory.

Methodology

Grounded theory is defined by Chenitz and Swanson (1986, p. 3) as “a highly systematic research approach for the collection of qualitative data for the purpose of generating explanatory theory that furthers the understanding of social and psychological phenomena”. The aim of grounded theory is to develop theory that explains basic patterns of social life. Grounded theory “reveals the hidden meanings embedded in peoples’ actions as they deal with the basic social problem that they share” (Schreiber & Stern, 2001). Grounded theory provides the means by which the researcher can go beyond past experience, “to move it from a description of what is happening to understanding the process by which it happens” (Artinian, 1998, p. 5).

Grounded theory has been used by a wide variety of researchers to identify basic social and psychological processes related to the area being studied. Fleury et al. (1995) used grounded theory to describe and analyse the social and psychologic processes used by women during recovery from an acute cardiac event. Grounded theory was used to examine the meaning of spirituality for patients recovering from a heart attack, and how their perceptions of spirituality influenced recovery (Walton, 1999), as well as to examine factors which patients viewed as enabling or disabling their life-style changes for health promotion during cardiac rehabilitation (Frenn, Borgeson, Lee & Simandl, 1989). Grounded theory analysis has also been used to identify the experiences and needs of women with coronary artery disease (Murray, O'Farrell, & Huston, 2000).

In grounded theory researchers are encouraged to formulate their own interpretations based on the understanding of their participants, rather than focusing on what they found in a review of the literature (Schreiber & Stern, 2001). Glaser and Strauss (1967) do not recommend a comprehensive review of the literature prior to formulating a research study because of the risk of the researcher being swayed by preconceived ideas about what they may find in the data. However, more recently authors suggest that a literature review is necessary (Chenitz & Swanson, 1986, Schreiber & Stern). A review of the literature related to the area being studied is not only an academic requirement, but provides supporting evidence related to the “scope, range, intent and type of research” completed to date and the background, purpose and significance of it for the study (Chenitz & Swanson, p. 44). Performing a review of the literature also expands the researchers ideas about the topic being studied and helps to promote theoretical sensitivity, which is discussed later in this chapter. Information gained from the initial literature review related to women and cardiac rehabilitation has been incorporated into chapter one of this thesis.

A further literature review is performed as data is analysed. This review focuses on literature that is relevant to the emerging categories. According to Chenitz and Swanson (1986), the purpose of this review is to use the literature as a source of data to verify and elaborate categories; to elaborate on and learn more about the area's structural conditions; and finally to discover and learn about related subjects as they arise. This allows the developing theory to be placed in context with existing theories and work related to the topic being studied (Chenitz & Swanson). Glaser and Strauss (1967, p. 168) suggest that

literature in a grounded theory study should not be used alone “but in combination with data drawn from a *variety* of different sources” (original emphasis). Literature is gathered and compared with emerging categories in order to improve the rigor of findings (Schreiber & Stern, 2001). The literature review in grounded theory “is specific and directed at each point” (Chenitz & Swanson, p. 45) and ongoing review of the literature assures that no data are missed. In this way literature is incorporated into the study as data.

Grounded theory uses an inductive and systematic approach, which involves theoretical sampling and constant-comparative data analysis, in order to generate theory about basic social processes (Glaser, 1999; Liehr & Marcus, 1994). Theoretical sampling, sometimes called purposive sampling is used in grounded theory in order to gain information about the phenomenon of interest and involves the researcher deliberately seeking certain types of participants (Davidson & Tolich, 1999; Polit & Hungler, 1999). Theoretical sampling is further defined by Glaser and Strauss (1967, p. 45) as “the process of data collection for generating theory whereby the analyst jointly collects, codes and analysis his (sic) data and decides what data to collect next and where to find them in order to develop his theory as it emerges”. This allows the researcher to select participants that will help to broaden the range of data obtained (Glaser & Strauss). Theoretical sampling is appropriate when collecting data in order to describe the lived experience of individuals experiencing the phenomena of interest. As categories emerge, certain groups or subgroups are targeted so that the researcher is able to test and refine the emerging categories (Liehr & Marcus; Schreiber & Stern, 2001).

In grounded theory the researcher uses a variety of different techniques to obtain data, including interviews, participant observation, focus groups, memoing, field notes, and the examination of documents and literature (Schreiber & Stern, 2001). Gathered data is then analysed using the constant-comparative method developed by Glaser and Strauss (1967). Glaser and Strauss (1967) describe the following four stages of the constant-comparative method of data analysis. Stage one involves coding each incident into as many categories as possible or fitting into an existing category. Open coding “is the initial step of theoretical analysis that pertains to the mutual discovery of categories and their properties” (Glaser, 1992, p. 39). Therefore open coding identifies major categories and subcategories. Chenitz and Swanson (1986, p. 94) define categories as “abstractions of phenomena

observed in the data". Stage two involves integrating categories and their properties, with comparison progressing from incident to incident, to comparison of the incident with properties of the emerging categories. Codes are grouped into clusters by similarities and differences. These clusters then form the initially identified categories.

Coding for variation and the range of extremes is then done. According to Chenitz and Swanson (1986, p. 123) this involves "looking for instances of the category and comparing these instances with each other in order to note the similarities and differences that recur in the data". Substantive codes are defined by Glaser (1992, p. 27) as "the conceptual meanings given by substantive generating categories and their properties". Substantive codes are generated from these categories and identify patterns found in incidents within the data (Glaser & Strauss, 1967).

Glaser and Strauss (1967) suggest that after coding and comparing a category, coding should be stopped and a memo recorded detailing any ideas the researcher has on the category. Memos are used throughout the coding process to capture ideas and document recurring themes throughout the data analysis process. Field notes should also be recorded and reviewed during data analysis. Data are then analysed and reanalysed for categories, descriptions and basic social processes (Chenitz & Swanson, 1986; Polit & Hungler, 1999). Data gathering is complete when data saturation has been reached. Saturation means that the categories that emerged from the data are full and no additional data are being found that could be used to develop the properties of these categories (Glaser & Strauss, 1967; Schreiber & Stern, 2001).

Method

Grounded theory was considered the most appropriate method for this research study because it is suitable to use when there is little prior knowledge of the topic (Chenitz & Swanson, 1986). Women's perceptions and experiences of cardiac rehabilitation have not been investigated in any depth in New Zealand and only limited research has been done overseas. Grounded theory is used here to examine women's perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack in the hope that it will identify basic social processes affecting women's attendance and participation in cardiac rehabilitation programmes.

Eligible participants were women admitted to two North Island hospitals with a diagnosed heart attack. All participants had been referred for phase two cardiac rehabilitation, and eight out of the ten had attended one or more sessions. Prospective participants were approached by a cardiac rehabilitation nurse prior to, or after discharge from hospital and given a letter explaining the study (appendix 2). Included with the letter was a stamped self-addressed envelope and a reply sheet (appendix 3). A break down of participant's ages is given in table 3.

Table 3: Age Range of Participants

Age Group	50-59	60-69	70-79	80-89
Number of Participants	2	1	4	3

Prospective participants were asked to either ring me or to return the reply sheet indicating that they agreed to discussing this study further. Prospective participants were not approached during the acute phase of their illness; when still in the intensive care unit (ICU) or coronary care unit (CCU); if they were considered by nursing or medical staff to be medically unstable; or having recurrent episodes of cardiac chest pain. This approach is supported by the National Heart Foundation of New Zealand who suggests that patients should not be approached for cardiac rehabilitation until they are symptom free and able to begin discussing their condition (NHFNZ, 2000).

It was anticipated that all participants would have received inpatient (phase one) cardiac rehabilitation. Participants may or may not have had a previous heart attack, and may or may not have attended cardiac rehabilitation in the past. The purpose of not limiting participants to those who had suffered their first heart attack was to see if there were differences in perceptions between participants who have had their first heart attack and those who have had two or more. Out of the ten women who participated in this study, three had experienced more than one heart attack. Non-English speaking participants were not included due to the cost and lack of availability of translators.

It was intended that the initial interview would be within 3 months of discharge from hospital after their heart attack. However many of those who replied to my letter of introduction had suffered their heart attack up to three years ago. In theoretical sampling “the researcher does not screen people in and out of the sample based on predetermined criteria” (Schreiber & Stern, 2001, p. 183) but works from an emic perspective and accepts as initial participants those who identify themselves as being knowledgeable about the topic being studied (Glaser, 1978). Therefore because these women felt as if they were recovering from their heart attack and identified themselves as prospective participants they have been included in the study sample.

The number of participants was limited by the small number of women available who met the inclusion criteria. There were initially twelve prospective participants however one withdrew from the study due to ill health and prior to the first interview and a second was unable to be contacted to arrange an interview time. No further participants were forthcoming during the time allocated for this part of the study.

Data Collection

Data were obtained for this study through semi-structured in-depth interviews. Kvale (1996, p. 1) suggests that:

In an interview conversation, the researcher listens to what people themselves tell about their lived world, hears them express their views and opinions in their own words, learns about their views on their work situation and family life, their dreams and hopes.

According to Kvale, the aim of the qualitative research interview is to attempt to gain an understanding of the world from the participant’s viewpoint, to uncover the individual’s lived experience and the meaning that this has for them. During the in-depth interviews the participant’s experience of their heart attack and cardiac rehabilitation was explored in the hope of uncovering the participant’s perceptions of the contribution of cardiac rehabilitation to their recovery. Follow-up interviews were held with two participants in order to clarify information obtained during the first interview and expand on developing categories. Written consent was obtained from participants prior to the commencement of the first interview. With the permission of the participants all interviews were audio taped

and then transcribed by a typist. Participants were able to view their transcripts if they requested to do so, however no participants requested this.

Interviews began with me asking the participant to talk about their experience of having a heart attack. They were then asked to tell me about their recovery. The semi-structured nature of the interviews allowed for changes in questions depending on answers received. This gave the participant and myself some control over the direction of the interview (Kvale, 1996). Interviews took place at a mutually convenient time for the participant and myself. Most interviews were held at the participant's home although one was at a participant's workplace. In all cases the interviews took place within an environment where the participants felt comfortable.

Rather than using theoretical sampling in its truest sense I used theoretical sampling to direct the questions asked during interviews in order to further develop and explore the emerging information. Questions initially focused on what I thought would be important in relation to cardiac rehabilitation. Table 4 shows the initial planned interview questions. These questions were used as a guide for the first participant's initial interview.

Table 4: Initial Interview Questions

Question 1	Can you tell me about your heart attack?
Question 2	Did you attend cardiac rehabilitation?
Question 3	(If yes) What made you choose to attend? (If no) what made you choose not to attend?
Question 4	What was cardiac rehabilitation like for you?

However after using these questions to guide the first interview it was apparent that these questions were too prescriptive and did not lead to the participant talking openly about their experience. Table 5 provides an outline of the questions used to guide later interviews. These questions were used to initiate participants' conversation about their experience of cardiac rehabilitation. They were not necessarily used or worded in exactly the same way for every interview, but rather they were used as a guide. The actual questions asked depended the participant's responses. These questions encouraged participants to talk about their experience and perceptions of both their heart attack and the cardiac rehabilitation they received.

Table 5: Final Interview Guide

Question 1	You have had a heart attack, can you tell me about it?
Question 2	As you started to recover, what things did you find helpful for your recovery?
Question 3	What didn't help your recovery?
Question 4	In a couple of sentences could you sum up what we've said today?

Along with interview transcripts, field notes were also documented after each interview. The field notes contain key phrases or sentences, descriptions of the situation, body language and things that happened during the interview, which may not be explicit on the tape-recording. Field notes can be used as data or to jog the memory of the researcher and are included in the data analysis (Chenitz & Swanson, 1986; Polit & Hungler, 1999). Initial field notes were written in a notebook. After the first five interviews field notes were tape-recorded and I transcribed these. Table 6 provides an example of a field note:

Table 6: Field Note Example

'This interview went well. This lady hasn't attended cardiac rehabilitation but she seems interested in going to see what it is like. She talked a lot about stress and wanting to know the cause of her heart attack. Need to arrange a follow-up interview. This interview took place in a quiet work place and I get the impression that there was a lot of work stress' (2.1).

Data for analysis was also obtained through the use of memos during the data analysis phase. Theoretical memos were recorded in order to keep track of thoughts and questions related to data collection and analysis. An example of a theoretical memo is provided in table 7.

Table 7: Theoretical Memo

2.1 This participant had a severe haematoma and this was an important event for her, which seemed to have a significant impact on her recovery. She seems to think that the haematoma is a small price to pay for being alive and being well.

- Why did this have an impact on her recovery from a heart attack?
- What is it about having other medical conditions that affects recovery from a heart attack?
- Is this effect always negative?
- What is the significance of the haematoma for her?
- How has it limited or changed her lifestyle?
- What price is too large a price to pay for health?

Data Analysis

The method of data analysis used in this study was constant-comparative analysis. Constant-comparative analysis involves the joint collection and analysis of data using “explicit coding and analytic procedures” (Glaser & Strauss, 1967, p. 102). Taken in its truest form this involves collecting interview data and then analysing it before commencing the next interview. Where possible this was done, however the time taken for the interviews to be transcribed meant that this was not always possible and interviews were done in groups of two or three while previous interviews were being transcribed.

According to Glaser and Strauss (1967), the constant comparative method can be used to create theory in a systematic way. It was hoped that this research study would generate a substantive theory that describes women’s perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack. Substantive theory is described by Glaser and Strauss as theory that is developed for an empirical, or substantive area of enquiry such as patient care. First level coding was done using line-by-line analysis. Key words were underlined and then copied out on one side of the transcript.

Participant's words were then used to label the codes. An example of open coding is included in table 8.

Table 8: Open Coding example

Interview	Open coding	Initial category
<p>“ I am probably <u>not the typical heart attack victim</u>, in that I <u>actually didn't have pain</u>, I was <u>out in the garden, and got visitors</u> and it came and it was the most beautiful summers day and <u>I came in and entertained</u>, it must have been for about 2 hours and then when they had gone, it was about 5 at night and <u>I thought I will just go out and put everything away</u>” (4.1:3-7).</p>	<p>Not typical heart attack victim. Actually didn't have pain. Out in the garden, got visitors. Came in and entertained. I thought I would just go out...put everything away.</p>	<p>Not typical. Didn't have pain. Put everything away</p>

Codes were then examined and formulated into initial categories. Table 9 shows the initial categories and their properties. Each incident was then compared with the emerging categories in order to further develop them and check to see if they fitted. The relationship between categories was then examined and final categories and subcategories developed. The substantive codes that emerged during this phase were related to symptom significance, recovery and support.

Stage three involves delimiting of the emerging theory. This occurs by clarifying data, taking out non-relevant properties, integrating and reducing categories. Table 10 shows the final categories and subcategories, which form the basis of the data analysis chapters to follow.

Table 9: Initial Categories and Subcategories

Categories	Subcategories
Feelings of powerlessness and frustration.	<ul style="list-style-type: none"> • Powerlessness and frustration. • Trying to protect others. • Stressed at not being able to do the things they want to. • Weren't given information and would have liked more.
Perception of illness and the effect this had on prioritising and decision-making.	<ul style="list-style-type: none"> • Symptoms were different to what they expected. • Didn't realise they were having a heart attack. • Didn't think the heart attack was serious. • Stopped what they were doing. • Why me?
Relationship between perception of illness and perception of recovery.	<ul style="list-style-type: none"> • Relationship of illness perception to decision making related to recovery. • Didn't feel ill so didn't need to recover. • Effect of other illnesses on recovery. • Coming to terms with being ill and having to recover.
Influence of social factors on cardiac rehabilitation attendance.	<ul style="list-style-type: none"> • Influence of cost. • Attended to please others. • Didn't attend because of social roles. • Wanting to know more about cardiac rehabilitation before attending. • Putting things off. • Better things to do with time.
Needing to feel supported.	<ul style="list-style-type: none"> • People provided support and encouragement for recovery. • Felt enabled by cardiac rehabilitation. • Importance of having time to attend and recover. • Negative aspects of feeling alone, feelings of isolation. • Felt uncomfortable at first, didn't discuss personal information so had little knowledge of the experience of others.
Concrete positives and negatives to attending cardiac rehabilitation.	<ul style="list-style-type: none"> • Thought it was interesting and useful for recovery. • Felt annoyed with some of the things that happened and didn't enjoy some aspects. • Information and lack of information while still in hospital. • Heard the information before from other health professionals, didn't take much notice.

Finally stage four involves the development and collation of memos into categories, which in turn become major themes of the developing theory. It is at this stage that theoretical codes emerge from the data analysis (Glaser & Strauss, 1967). Theoretical codes are defined by Glaser (1992, p .27) as “the conceptual models of relationship discovered to relate the substantive codes to each theoretically”.

Table 10: Final Categories and Subcategories

Significance of symptoms	Women don't have heart attacks. Interrupted activities. Is this a heart attack?
Dichotomy of recovery	Why me? Finding something to blame What does recovery mean for me? Restricted roles.
Regaining everydayness	Disruption of everydayness. Coping with other illness. Carrying on. Being supported.

Available literature about the substantive area being researched was also collected and included in the data analysis. All forms of data were coded and compared for instances of the substantive categories. Data collection and analysis continued throughout the process of writing this thesis. However, data saturation was not reached due to the limited number of participants and short time frame of this study.

Generalisability, Fit, Credibility and Trustworthiness

Due to the nature of qualitative analysis the terms reliability and validity are not applicable. They are replaced by terms such as generalisability, fit, credibility and trustworthiness. According to Chenitz and Swanson (1986, p. 13), "in grounded theory, generalisability is handled by detailed description during the data collection and assigning membership to a class or unit to the case under study". The best way to achieve this is through comprehensive theoretical sampling (Chenitz & Swanson). It is hoped that by using theoretical sampling that covers a wide range of information from a variety of sources, such as different participants and literature, the data are more readily generalisable to other women who have had a heart attack and received cardiac rehabilitation.

The developed theory should provide categories and hypotheses that are clear enough to be verified in current and future research. Developed theory should also be understandable to both professionals working within the substantive area and lay-people (Glaser & Strauss, 1967). It is also necessary for the theory to fit the situation that is being researched and to work when it is applied to that situation. According to Glaser and Strauss (p. 3) 'fit' means, "the created categories must be readily (not forcibly) applicable

by the data under study". They suggest that 'work' means the categories must be relevant and meaningful and provide explanation for the behaviour under study.

Trustworthiness is the degree to which research findings are deemed to be worth paying attention to and is seen as being true from the perspective of the participants. According to Denzin and Lincoln (1994, p. 508) "trustworthiness consists of four components: credibility, transferability, dependability and confirmability". Therefore research results are trustworthy when able to be confirmed by participants and others with similar experiences. Sandelowski (1986, p. 30) suggests that, "a qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having the experience would immediately recognise it from those descriptions as their own".

Participants were sent a summary of the study findings in order to see if they reflected the perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack. Participants were able to relate to different aspects of the categories and basic social process that emerged from the data. Findings were also discussed with other women who had either personal experience of a heart attack or a female relative had suffered a heart attack to see if the results related to their experiences. Feedback showed that other women had similar experiences to those of participants.

The credibility of this research study was presented through the use of an audit trail. By using an audit trail "the investigator is responsible not only for the results but also for explaining how the results were obtained" (DePoy & Gitlin, 1994, p. 278). An audit trail can be used to determine dependability and confirmability (Lincoln & Guba, 1985). Memos have been used to form an audit trail to enable data collection and analysis steps to be retraced (Cutcliffe & McKenna, 1999).

Lincoln and Guba (1985) discuss six categories of an audit trail. Information related to five audit categories was used to guide the development of an audit trail, including: raw data, in the form of tape recordings of interviews and field notes; data reduction and analysis products in the form of field notes, quantitative summaries and theoretical notes; data reconstruction and synthesis products in the form of categories, conclusions and

integration of existing literature; process notes including methodological notes and audit trail notes; and finally, materials relating to intentions and dispositions, in the form of the research proposal, expectations and personal notes.

Transferability refers to whether the results of research can be applied to different situations or populations (Lincoln & Guba, 1985). It is not possible to predict the transferability of this type of research, as the researcher cannot know how or where others may seek transferability. Lincoln and Guba (p. 298) suggest that “if there is to be transferability, the burden of proof lies less with the original investigator than with the person seeking to make an application elsewhere”.

Ethical Issues

Prior to commencing this research study ethical approval was obtained from the relevant regional ethics committees (approval 17/01) and the Massey University Human Ethics Committee (approval 01/90). Ethical issues related to research include gaining the informed consent of participants, maintaining privacy and confidentiality, causing no harm, and truthfulness and social sensitivity (Massey University Human Ethics Committee, 2000; Tolich & Davidson, 1999).

Letters of support were obtained from the cardiac rehabilitation nurses involved in accessing participants, the Medical Directors of the coronary care units and permission gained from the Chief Executive Officers of both hospitals. A letter of support was also obtained from the National Heart Foundation Cardiac Rehabilitation Manager and the research proposal was scientifically reviewed.

Participants were informed of the study purpose via an information sheet (Appendix 4) and written consent obtained (Appendix 5). It was made clear to participants that participation was voluntary and they were able to withdraw from the study at any time prior to the end of the second interview. The participants were assured that their medical and nursing care will not be affected in any way if they chose to withdraw.

Chenitz and Swanson (1986, p. 158) suggest that “human subjects have the right to know what will happen to them if they decide to participate in an investigation”. Further

information about the study was given to participants on request and any questions they had were answered at the time of the interviews. Participants were also able to contact my thesis supervisor with any concerns or queries.

Confidentiality is an important issue when dealing with data obtained from human participants. Dealing with raw data requires a high degree of thought about confidentiality, informed consent, and protection against the abuse of raw or coded data (Boyatzis, 1998). For the purposes of this study, confidentiality was maintained by limiting access to raw data to myself, my research supervisor and the person transcribing the audiotapes. The transcriber was required to complete a confidentiality declaration (Appendix 6). All written data is kept in a locked filing cabinet in my home. Electronic data is kept in files protected with passwords on my home computer. The transcriber was also asked not to keep a copy of any of the transcripts once the transcriptions were handed to me.

Anonymity was maintained by not using any information that may identify participants, such as name, date of birth, hospital or hospital admission date. All identifying information has been removed from transcripts as well as from this final thesis document. Information that might identify participants, such as consent forms was also kept separately from the data.

Harm was minimised by ensuring the participants knew their rights in relation to the research study. Participants were informed that they could stop an interview at any time for any reason. Because of the personal nature of interview discussions it was important to remain sensitive to the experience of participants and to give them control over what was recorded. On several occasions the interview tapes were stopped and then recommenced at the participant's request. Because of the possibility that participants might mention aspects of their experience that indicated poor nursing or medical care, the phone number of the Health and Disabilities Consumer Advocate was included in the information sheet. I suggested to one participant that she should ring this number and discuss some of the issues she had about the care she had received.

Summary and Conclusion

Grounded theory was chosen as the method for this study because it suited the research question and because there has been little research done looking at women's perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack. Ethical guidelines were followed in order to protect the participants from harm. Data collection included semi-structured interviews, field notes, memoing, and review of literature relevant to the emerging codes and categories. The first interview took place in September 2001 and the last in April 2002.

From the time of the first interview data has been analysed using the constant-comparative method originally outlined by Glaser and Strauss (1967). Data analysis was finally completed when all of the study results were written into this thesis document. Although each participant's experience was unique there were some similarities which formed categories. Categories emerged from the data related to symptoms and their significance. The following chapter examines the participant's perceptions of the significance of their symptoms.

Chapter 3

Different Expectations: Symptoms and their Significance

Introduction

"I mentioned to (CR nurse) I have already been (to cardiac rehabilitation) but you know, I will go again, and they were women that were there, there might have been one man, but most of them were women".

(Dorothy, 1:296-299)

Many women are surprised when they suffer a heart attack. The focus on men and heart disease has been so strong in the past that when women experience symptoms that cause them distress they often do not consider that heart disease is a possible cause. The classic symptoms for a heart attack are commonly described as shortness of breath and central crushing chest pain with radiation to one or both arms, jaw, neck or back (Cummins, 1997). Pain may also be accompanied by nausea and vomiting (Petrie & Weinman, 1997). However, women having heart attacks present with a variety of different symptoms including fatigue, shortness of breath, back pain, oedema, and transient non-specific chest pain (Miller, 2002). As these symptoms differ from the classic symptoms of a heart attack they are often discounted by health professionals.

Prior to discussing their experience of cardiac rehabilitation the participants in this study talked about their heart attack. It was necessary for them to work through and explain their whole experience rather than just focusing on cardiac rehabilitation. As a result of this, rich data was collected about their experiences and perceptions of suffering a heart attack. This chapter examines data related to the experiences and perceptions of symptoms and their significance for the women in this study.

Women Don't Have Heart Attacks

Symptoms hold a different significance for health professionals than they do for those suffering them. Knowledge related to the anatomy and physiology of the heart and experience in dealing with people suffering from heart attacks is combined with hospital assessment and treatment protocols to provide health professionals with a frame of reference for symptom recognition and management. This framework is highly medicalised and revolves around assessment, treatment and recovery. As a result, the focus of health professionals is largely on providing emergency medical care during the acute phase of the heart attack and then education about risk factor modification in order to prevent further heart problems. This focus is demonstrated in the information given to people who experience a heart attack (Silverstone, 2000) and the health professionals who provide nursing and medical care (NZGG, 2002b). Because of the risk of cardiac arrest all heart attacks are treated as serious, and greater significance is placed on the more classic symptoms.

Health professionals also make broad assumptions about the significance that symptoms of illness hold for people. These assumptions imply that people should be able to recognise the origin and cause of all the symptoms they experience. However the expectation that people will be able to diagnose themselves is not realistic when you consider the lengths that health professionals need to go to prove someone has actually suffered a heart attack. Diagnosis of a heart attack is generally only made after a physical examination, and a series of ECGs and blood tests are completed (Silverstone, 2000). It is therefore interesting that health professionals expect people with these symptoms to recognise the cause and seek treatment.

Eight of the ten women interviewed in this study did not realise they were suffering a heart attack. Of the two who did consider this, only Elizabeth was really sure enough to seek advice from friends and health care professionals.

"I had felt reasonably normal during the day and about half past seven at night I got this intense pain down my arm and I thought 'hello!' so I rang the duty doctors in town and explained the symptoms and I said "do you think I am having a heart attack?"

(Elizabeth, 1:7-11)

All of the women in this study recognised that the symptoms they were experiencing indicated there was something wrong, but not all recognised the significance. Some sought immediate medical assistance whereas others delayed seeking help until they really felt compelled to do so. Those who recognised that the symptoms they were experiencing may be related to a heart attack, sought assistance earlier than those who did not.

“I had just dropped off to sleep and I woke up and I couldn’t breathe. Well, it felt as though someone was sitting on my chest. I thought huh! I felt my pulse, it was bouncing around and I just thought, well, is this a heart attack? or what is it”.

(Ruth, 1:2-5)

Health professionals do not seem to investigate or treat women’s symptoms with the same degree of importance or urgency as those experienced by men. In fact even when chest pain is a significant symptom for women it is often perceived as being benign (Caves, 1998; Jensen & King, 1997). The narrow view of signs, symptoms and at risk populations focused on by health professionals, has limited the information given to people about heart attacks and heart disease. This is particularly applicable for women as information is still being offered in a way that implies men are the target audience and the most at risk population.

Even recent Heart Week campaigns have focused on men and used men as examples (“Heart Week 2002”, 2002). It appears from pamphlets produced by the NHFNZ that when women are targeted for information it is more often about other types of heart disease, such as valve replacements and heart failure, rather than heart attack. An example of this is the pamphlet “Give Your Heart a Fresh Start: Information about cardiac rehabilitation” (NHFNZ, 1997), which gives examples of men who have suffered heart attacks and provides one example of a woman who has had a heart valve replacement. As a result, women do not necessarily recognise that there is any risk of them suffering a heart attack. When the symptoms women develop are different, or not as severe as they would expect with a heart attack, they may not recognise the cause.

This point is accentuated by a comment from Beth:

“Perhaps women should be made more aware of the fact that... of what it is, I mean if a man started having pains in his chest, and carrying on, you would naturally think that he is having a heart attack, but women as you say don’t think of heart attacks”.

(Beth, 2:98-101)

This comment suggests that Beth believes women are not aware of their risk for suffering heart attacks.

The experience of chronic illness also had an effect on participants’ perceptions of symptoms. Women who had suffered from long term or chronic illness viewed symptoms differently from those who had been well prior to their heart attack. For women with long term or chronic illness, those symptoms took on greater significance than the short-term, acute symptoms of a heart attack.

“But it is all my things that I have got wrong with me, and the thing is, I don’t really feel ill, I don’t feel that I have got anything wrong with me, it is just these, you know the rheumatism that is the worst, it is a real nuisance really”.

(Kathy, 1:169-172)

Julie was suffering from acute neck pain with associated loss of movement:

“Well it has been far worse than the heart attack. There is a pain in my neck, up there, and into my shoulder and then just recently I couldn’t use my arm for about a week”.

(Julie, 1:45-47)

The significance of symptoms was mediated by what the women believed their cause to be. Rosie placed significance on her respiratory symptoms because she thought she had inhaled weedkiller. She did not consider the other symptoms she was experiencing were significant in relation to what she thought was the cause and did not tell health professionals about them.

“They kept saying ‘are there any more sensations?’ Well because they weren't painful and because I actually thought perhaps I had imagined them, um...and I could see that they were going to give me a drip, I said ‘no’. But there was, I mean, there was no pain and I think that is why I am not the typical and I had always imagined pain down the arm, or something like that if you have a heart attack, yeah, no I felt perfectly good, I felt as though I should not have been in hospital”.

(Rosie, 1:38-44)

In contrast, symptoms that were not significant to Rosie were obviously significant to the health professionals hence the reason they kept asking her questions about how she was feeling. Failure of health care professionals to quickly and accurately diagnose may have also contributed to participants' discounting their symptoms (Faller, 1990).

Interrupted Activities

How women respond to symptoms is intrinsically linked to their perception of the significance of those symptoms. Most of the women in this study found the symptoms they experienced were significant enough to make them stop what they were doing, but this did not mean they sought immediate advice or medical care. Rather, assistance was sought some time after the event or as the symptoms persisted or severity increased. When the distressing symptoms subsided the women carried on with their activities. This may be related to their role expectations, needing to complete whatever it was that they were doing, or to wanting to have some degree of control over what was happening to them. It may also be related to not defining the symptoms as a significant health problem.

Nicola provides an example of this:

“I thought my bra strap was too tight. But it was when I started getting very breathless, very breathless and I couldn't walk up to the shop in the village there without stopping. Well one day and I just went into the chemist and said 'can I sit here for a while?' and I told my doctor (...) and he was in contact with me every day and it was on the Saturday afternoon when I suddenly had this sort of a square pain and that was the first day and I didn't think it was a heart attack! I just waited until it had gone and got on with the ironing”.

(Nicola, 1:140-148)

Dempsey, Dracup and Moser (1995, p. 450) suggest that rather than denying the presence of symptoms, women minimise the importance or ascribe them “to a cause less anxiety provoking than the heart”. This results in denial of the possibility that the symptoms experienced could be related to a life threatening illness.

“I had a friend coming for lunch and I thought I would make a quiche. So I got the quiche half made and I said to my husband “oh I don't feel well”, he said 'shall I call the doctor'. I said 'I'm not sick like that'. I was all sweaty and headachy and ah...he said 'well come and sit down for a while'. So I went and sat down for a while, sat down for about half an hour. I said 'oh I feel better now so I'll go ahead getting lunch'”. So I finished making the quiche and ... and (friend) came and I felt all right. I felt a bit lifeless but otherwise I was all right and I didn't have much lunch”.

(Rachael, 1:7-13)

The significance of the symptoms increased dramatically when performing a task participants were unable to stop doing, causing extra stress and anxiety, and removing feelings of control.

"I had an attack out while I was driving the car and it was really bad and I couldn't stop because I was on the bridge, I tried to fish into my bag to get my (Nitrolingual) spray...and do I stop or do I just keep going and this pain just getting worse and worse. I had to think should I stop? I think that made it worse. Um...I got ...I eventually got the spray and got home and sat in the car".

(Beth, 1:284-288)

It is often assumed, by health professionals and the general public, that those who have experienced a previous heart attack will recognise and relate any future symptoms to the same cause. However this was not the case for the women in this study. Symptoms experienced by participants were not always constant or the same. For some women symptoms changed as their heart attack evolved. For others, symptoms changed with subsequent heart attacks. The variable nature of symptoms experienced by participants meant that new symptoms did not hold the same significance for them as those previously felt.

"I had pains from my chest, really bad pains, and that went through to my back but the last time it sort of started in my back and then later on it went through to my chest more".

(Dorothy, 1:2-4)

This meant participants did not necessarily react to symptoms in a way that health professionals might have expected because they did not realise they were having another heart attack.

“Just sitting having breakfast with the first one and I had only had a Kiwi fruit, that was all and I was thinking it might be indigestion but it wasn’t and the second one I was in the shower. Well, I think I got to the stage where I turned the shower down just before I got out and I got these bad pains in my back and I hoped I might have put a disc out or strained a muscle and I went back to bed”.

(Dorothy, 1:7-11)

Therefore participants who had suffered from some type of heart problem in the past did not have an advantage when it came to recognising the origin of their symptoms. For some their previous experience only added to their confusion. This was the case for Rachael:

“While I did have pain of a sort, it was like a lump that um...when I have angina. I had been having those for about 18 months beforehand. A dose of bicarbonate in a glass of water would fix that”.

(Rachael, 1:60-62)

An Australian based study examining delay in response to heart attack symptoms supports the finding that previous experience of a heart attack does not necessarily assist with recognition of symptom cause. Findings showed there was no difference in the average time taken to arrive at hospital between participants with prior experience and knowledge of heart attack symptoms and those without experience or knowledge (Dracup, McKinley & Moser, 1997).

Being unable to identify the cause of their symptoms made it difficult for participants to decide what to do about them. Decision-making was related to past experience of self, family and friends as well as knowledge about symptoms and individual interpretation of the possible severity of the problem. Women may also not seek medical care because they perceive their symptoms as insignificant (Dempsey et al., 1995).

Is This A Heart Attack?

Participants in this study had a strong concept of what they thought the symptoms of a heart attack should be like. The symptoms experienced by each individual were interpreted based on their prior knowledge and experience of similar symptoms.

“Pains down my arms I suppose. You see, with the second one I had it was all across the shoulders and I was in very great discomfort there, across my shoulders and I was sweaty and I had quite a lot of pain but I always imagined it would happen around here (chest), you know”.

(Nicola, 2:151-154)

Experiencing symptoms that were different to what they thought were typical heart attack symptoms caused confusion when participants were admitted to hospital, and told of their diagnosis. Several participants found it very hard to believe they had really suffered a heart attack. When they did not experience what they thought were ‘typical’ symptoms they could not relate their symptoms to a serious illness. Rosie, in particular, felt she was not a ‘typical heart attack victim’. It was also clear from her interview that Rosie did not view herself as being especially ill.

“I felt light headed and it wasn’t a pain, it was just a sensation in my throat. Definitely no pain, but I see people that probably really care for themselves after a heart attack are those that have had pain or something that has frightened them (...) No, I just feel that I am probably not your typical heart attack victim by any means”.

(Rosie, 1:351-368)

Shock and disbelief at having suffered a heart attack were common feelings among participants.

“Well I felt very indignant. To think that I should have a heart attack. I think because I had never had any heart trouble and I just felt why the dickens should this happen to me? I have enough on my plate without this. And mind you, I don’t lie down easily and accept things so that probably has a lot to do with my recovery”.

(Elizabeth, 1:104-108)

These perceptions are supported by research that investigated the common experiences and needs of women with CHD, with most participants emphasising the difficulty they had in recognising their symptoms were caused by heart disease (Murray et al., 2000). It is clear the women in this study expected to suffer classic symptoms when having a heart attack. Miller (2002) suggests this may be because chest pain and other classic symptoms are what they are told to expect by health care professionals and the media. The symptoms that participants experienced did not match their expectation that they would experience the same symptoms as men. McSweeney (1998) found that women believed only severe left sided chest pain and left arm pain was indicative of a heart attack occurring.

It has been suggested that women do not seek immediate medical assistance for symptoms of a heart attack because they experience feelings of denial about the significance of those symptoms (Dempsey et al., 1995; Rosenfeld & Gilkeson, 2000). However rather than being in denial it has been suggested that the individual’s frame of experience may simply be different to that of the health professional (Jairath, 1999). People experiencing a heart attack may simply have difficulty identifying the cause of their symptoms and attribute them to other causes such as indigestion (Dracup et al., 1997). Jairath suggests that unless individuals incorporate potentially protective aspects of cardiac pain into their frame of experience there is a potential for inappropriate responses or denial when subsequent pain occurs.

Another barrier to seeking or receiving care was the response from health professionals. Several participants also found their General Practitioner (GP) did not place a lot of

significance on their symptoms and failed to recognise initially that they were caused by a heart attack. It has also been suggested that delays in seeking treatment may be related to women not experiencing symptoms in the same way men do or to difficulties with communicating symptoms to health professionals. Although research suggests many women do experience chest pain (Meischke, Larsen, & Eisenberg, 1998; Miller, 2002; Penque et al., 1998), it may be that it is not the most significant symptom for them and as a result of this they may not seek advice or assistance (Miller). Delay may also be related to women's beliefs that they are not at risk for developing heart disease (Penque et al.).

Another New Zealand researcher investigated what information patients and their partners wanted to receive following a heart attack (Phillips, 2000). She noted that the women in her study experienced a delay in recognition and diagnosis of AMI by health professionals and that, once diagnosed they were not given adequate pain relief. Phillips suggests that the clinicians' 'framework of experience' failed to accommodate what was happening to these women. This may occur as a result of symptom management and treatment strategies being based on research of male only populations (Halm & Penque, 1999).

The women interviewed generally expected the symptoms of a heart attack would be very severe rather than the more mild symptoms they experienced.

"Mind you I really feel that mine was more of a..., I know heart attacks are serious but mine was more mild than serious because you know, you read in the paper quite often that somebody died suddenly of a heart attack and they just collapse and die and that is that, whereas I got my heart pains, I got myself down to the doctor, I drove myself down and I could have really, if I'd had to, driven myself to the hospital".

(Kathy, 1:406-411)

Education related to heart attacks has often been linked to information about cardiac arrest and cardiopulmonary resuscitation. Such a link has been perpetuated by documents such as the New Zealand Resuscitation Council's guidelines for cardio-pulmonary resuscitation (CPR) (New Zealand Resuscitation Council, 2000). This book contains information on the classic signs and symptoms for a heart attack and by its very nature links them to cardiac

arrest. As a result of this link people may believe that cardiac arrest and heart attacks are the same thing. The risk of this type of belief is that heart attack symptoms may be treated as minor because the person experiencing them has not suffered a collapse or a cardiac arrest. Several researchers note that the symptoms experienced by women are not as severe as they would expect for a heart attack (Johnson & King, 1995; LaCharity, 1999; Murray et al. 2000), as a result of this many women have difficulty identifying symptoms and delay in seeking care. They simply do not attribute their symptoms to such a serious cause (Dempsey et al., 1995; Dracup et al., 1997).

From my experience both health professionals and the general population have linked the severity of symptoms to the severity of disease. This is an assumption that has been made rather than a scientific link. There is a belief that having a heart attack will change the sufferer's life dramatically and irreversibly. This belief is perpetuated by education campaigns, such as Heart Week ("Heart Week 2002", 2002) and cardiac rehabilitation programmes, which focus on the need to make drastic lifestyle changes such as those taught by the NHFNZ (2000). This type of information has led to participants believing that if they do not have severe pain then they are not ill and if they experience lots of pain then they are ill.

"I mean I wish that I had had pain. I wish that my pain had been so severe that it would have jolted me out of smoking".

(Rosie, 1:162-163)

Pain as a symptom did not seem to be greatly significant for most of these women, with the exception of Beth who experienced continuing heart pain. However not having pain as a symptom was significant for Rosie. Both Rosie and Beth viewed pain as the defining symptom of a heart attack. In reality there is a broad range of symptoms and these can be quite different for each individual, as seems to be the case for many women and men. This adds to the problem that women have with recognising the cause of their symptoms.

These women's inability to give their symptoms a label made it difficult for them to know what to do about them.

"Well I didn't have pain that went down my arms and I didn't have a lot of pain either did I? I just felt uncomfortable and that things were not right with me but I wasn't short of breath or anything and my blood pressure was fine, so there wasn't really a lot to go on, was there, as far as we were concerned anyway".

(Julie, 1:182-185)

It appears that groups such as the NHFNZ have done an effective job of educating people in the community about heart disease. Literature suggests that people learn about the signs and symptoms of heart attacks through mass media, health care providers and health professionals (Dracup et al., 1997; Meischke et al. 2002). However this education has had a very narrow focus and has not met the needs of the whole community. This has in turn led to a lack of understanding regarding the variety of symptoms that may be experienced as well as the people who experience these symptoms.

"I expected that when anybody had a heart attack it was a terrific pain, you know. I did get a fright not long after I had had them because I had pleurisy and of course that gives you a terrific pain and I thought oh, here we go! You know. So I grabbed my puffer (Nitrolingual spray) you know and inhaled that, it didn't make any difference and the pain was still there and the penny dropped and I thought 'oh you are a stupid hen, it is the pleurisy' because I've always been prone to that. I have had that 2 or 3 times and I had it last week, pleurisy pain, it is just a pain but I mean that could be confused with a heart attack, you know I mean, because I presume that is more or less what the pain would be like, would it? I don't know.

(Ruth, 1:113-122)

Interpreting symptoms was also related to the past illness experiences of people they knew, which helped these women to interpret their own symptoms. Dorothy had an expectation that because her symptoms were similar to those her spouse had experienced, the cause would be the same.

“I thought it might be indigestion because my husband had a hiatus hernia. He had to have an operation for it and I, you know, I had the same pain as what he had in my chest and I thought oh, you know, it is indigestion but it wasn't”.

(Dorothy, 1:20-22)

However having relatives or friends who had experienced a heart attack did not necessarily increase the significance of the symptoms being experienced. It was only after diagnosis that participants related what had happened to them to the experiences of others.

“I don't even think I have ever thought about a heart attack, no, I mean my brother had one but I never even thought about how he felt”.

(Beth, 2:75-76)

Realisation of severity and possible consequences of suffering a heart attack was usually gained some time after the actual event. For Nicola this realisation seems to have been gained from attending the cardiac rehabilitation group rather than from what she was told while in hospital.

“I think it was, about the fact that I could have gone out on it. I think it was something that they said at the cardiac meeting made me realise that I was a bit lucky perhaps and perhaps if it wasn't that I had got the ambulance so quickly and was treated in A&E (Accident and Emergency) immediately it mightn't have been so good”.

(Nicola, 2:22-26)

Some participants realised the more serious implications of their symptoms when they were treated as being ill by health care professionals. Particular tests such as ECGs indicated to Margaret that there really was something seriously wrong with her heart.

“I realised that it was more serious than just unstable angina because they put the cardiograph on you and then the way that they look at each other, you could just tell and they rang the doctor immediately and he came up”.

(Margaret, 1:20-23)

Previous research found that participants were surprised about the nature of their heart attacks and expressed disbelief and shock at being told they had indeed suffered a heart attack (Wiles, 1998). As a result of not experiencing expected symptoms, Rosie has had difficulty with accepting the diagnosis of a heart attack. This may be related to denial, however the significance of symptoms is more complex than recognition or denial. The women in this study did not deny that they had symptoms. They just placed different levels of importance on them and reacted to them in different ways.

Summary and Conclusion

Many of these women seemed surprised they had suffered a heart attack. For most it was not the catastrophic event they thought a heart attack should be. Therefore even if women do recognise the cause of their symptoms, seeking immediate medical assistance may not be their priority. Continuing with what they were doing as soon as the symptoms subsided may indicate that they placed a greater significance on the activity they were engaged in, than on the symptoms they were experiencing. However it may also indicate that they did not recognise the significance of what was happening to them. Despite this, all of the participants in this study eventually sought medical assistance. The decisions of participants to seek assistance for symptoms appear to be related to several factors including knowledge of heart attack symptoms, severity of the initial symptoms, and having to stop what they were doing because of the symptoms. The following chapter examines data related to participants' need to identify a cause, or find a reason for suffering a heart attack. Also discussed are the differing perceptions of recovery between health professionals and study participants, and the effect this has on women's recovery from a heart attack.

Chapter 4

The Dichotomy of Recovery

Introduction

Most of the women interviewed for this study initially did not think they had anything useful to say about their heart attack and recovery but despite this they were happy to discuss their experience. As discussed in the previous chapter, the participant's perceptions of the cause of their symptoms affected their decision making related to seeking advice and medical assistance. Suffering a heart attack produced different effects on their lives. Participants looked for reasons why they had experienced a heart attack in order to clarify what the experience meant for them.

The women in this study tended to view recovery in a unique and different way to that of health professionals in New Zealand. In order to come to terms with their heart attack and the need to recover, participants firstly needed to identify a cause or find something to blame for what had happened to them. This chapter discusses the differing perspectives of recovery and the effect these have on recovery and rehabilitation after a heart attack.

Why Me? Finding Something To Blame

This involved searching for an explanation for why they had experienced a heart attack, and looking at who or what was to blame for their heart attack. For most participants this included actively searching for a cause.

Work stress and smoking were commonly identified as possible causative factors:

“So I’m no longer a smoker (laugh) of any description. Yes, I do believe it was a major contributing factor and the severe stress also from...from the business, given that it is our business and it’s not going well and that we’ve had serious financial problems all year so I believe that stress had a major part, but I do think that the main thing was the fact that I couldn’t stop smoking, even though I wasn’t smoking heavily, it was still smoking”.

(Margaret, 1:57-63)

Stress was also related to family life and everyday functioning:

“As I say, I attributed it to stress because I have got a very sick husband (...), I have got to do all the thinking for him and see to everything so I have a fair old burden on my shoulders and I think that contributed, you know, together with my daughter, to my heart attack”.

(Elizabeth, 1:18-27)

Some participants attributed their heart attacks to hereditary factors because other members of their family had suffered from cardiovascular disease.

“I really think my heart attack was a hereditary thing because my mother had a heart attack when she was only in her 50s and she died of a stroke but not until she was 80 and my dad died of a stroke when he was 72. My older brother had a heart attack when he was in his 50s and my younger brother died of a stroke when he was 60 so...”

(Julie, 1:151-155)

Medications were also mentioned by participants as being a possible cause for their heart attacks.

“I mean I was on (tablet name) and the doctor in hospital asked me how long I had been on them and I said ‘oh, about two and a half to three years’ and he said ‘well I want you to stop taking them as of now’ they are banned in America. They had caused cardiac problems. Now was my heart attack caused by taking those damn pills?”

(Beth, 2:460-464)

Kathy believed that she had a heart attack because she had been taking prednisone, but also that her heart attack had been caused by diabetes.

“I have had the heart attack and I think one has more or less, not given it to me, but predisposed towards it, and then of course, getting diabetes, I had a heart attack you see, so I blame it on the Prednisone and of course people say ‘oh no, that wouldn’t have been it’ but I don’t really believe that and I don’t like that drug and if I had really known the side effects from it I would never have taken it”.

(Kathy, 1:83-88)

It is clear that although finding a cause was important for participants it could also be difficult and confusing when there was more than one possible contributing factor identified. Finding a cause involved being able to find something or someone to blame, and this placed the responsibility for illness on something other than the participants themselves. This appeared to make it easier for these women to come to terms with what had happened to them.

Being able to blame lifestyle factors made it easier for some women to make changes to their lifestyles. However this was associated with feelings of guilt about possibly having caused the heart attack themselves. This guilt continued to occur even when most risk factors had been modified.

“I do feel terribly guilty with my family, because my family, well, the girls definitely don’t smoke but they have finally given up saying ‘please, don’t smoke’”.

(Rosie, 1:359-361)

Lack of understanding about what a heart attack was also led to confusion about the cause. Ruth felt that the pain she had suffered had caused the heart attack, rather than thinking that the pain was a result of the heart attack.

“Well I have had the two but that was while I was in hospital, suffering severe pain so I presume that it was the pain that caused the heart attack that time”.

(Ruth, 1:13-14)

In order to identify why they had suffered a heart attack participants reviewed the events leading up to the onset of symptoms, trying to decide if they had done something to contribute to the heart attack. Several participants felt that smoking and stress had contributed to their heart attack. Other research also suggests that part of the process and experience of heart attacks for women is trying to find a cause in order to find meaning for the event (Jackson et al., 2000; Rosenfeld & Gilkeson, 2000).

The women in this study seemed to need to identify a cause for what happened to them. Finding a reason for why they had a heart attack was part of living through a heart attack and getting back to normal life for these women. Finding a cause also involved reviewing the events associated with the heart attack and the decisions they made about seeking care for the participants in this study and other studies (Jairath, 1999). One of the themes that emerged from research exploring elderly women’s perceptions of having a heart attack

was “being hit with reality”, which involved the women seeking identification of “the reason for the change in their health” (Sutherland & Jensen, 2000, p. 666). Wiles (1998) also found that participants attempted to understand why they had suffered a heart attack.

For some this process also involved blaming themselves, blaming others and feelings of guilt. This does not only allow individuals to take responsibility for their heart attack, it also allows health professionals to apportion blame (Samson, 1999). If people do not make the recommended lifestyle changes, health professionals are then able to relinquish responsibility. When the individual suffers from further heart problems, health professionals blame them for their own ill health. For example, people who don't give up smoking or loose weight.

It is not only those who have heart attacks who search for something to blame. Health professionals also look for reasons, often blaming individuals for their own illness. Through this type of blaming people are seen as the instigators of their bodily misfortune. It has been suggested that blaming occurs with a wide variety of illnesses ranging from breast cancer and heart disease to contracting viruses such as the Human Immunodeficiency virus (HIV) (Gunderman, 2000).

Cardiac rehabilitation programmes may reinforce this blaming because they focus on risk factors and their modification. This focus on risk factors implies that the individual's behaviour can be blamed. Gunderman (2000) suggests that this happens whether or not the individual health care professional actually blames the patient, because the language used contributes to the presumption that responsibility lies with the patient. Blame was also placed on health care professionals who did not recognise or accurately diagnose the women they were caring for. Beth's anger and frustration was obvious when she talked about how her doctor had failed to diagnose her condition.

“You know the doctor not picking up that there was something. If I had had this pain on and off for a week, why didn't he investigate it further and just say, I mean, I said indigestion, that is what I thought it was”.

(Beth, 2:93-95)

Beth was still experiencing episodes of chest pain, which she found very distressing, and did not feel she had recovered well from her heart attack. As a result of this Beth perceived that her illness was not treatable and this added to her feelings of frustration and anger.

What Does Recovery Mean for Me?

'Recovery' is a term used commonly by health professionals to describe the time between becoming ill and returning to normal functioning. For health care professionals recovery is an active process that the patient engages in. It has been suggested that the recovery process is gradual and progresses over time (Kellmann, 2002). Cardiac rehabilitation regimes seek to control the recovery process of individuals who have suffered heart attacks by trying to convince them to make lifestyle changes that health professionals believe are desirable.

In contrast to this, recovery seems to be viewed by the general population as something that either will or won't happen to them when they have been ill. It is a passive process over which they have little control, which may or may not occur. For most people recovery appears to be facilitated by others (such as physiotherapy after an injury). Instead of "recovery" the participants in this study describe a state of returning to life. Rather than taking time to recover once discharged from hospital they describe falling or being pulled back into the life they had before. Therefore there appears to be a dichotomy in relation to the meanings and process of recovery after a heart attack.

Lunt (2000) talks about this dichotomy of recovery and suggests, even though rehabilitation may take into account the goals and preferences of individuals, its structure, "with its emphasis on skills and environment, is the genus of professionals, not consumers, not even consumer professionals" (p. 401). Therefore rehabilitation is not the consumer's view of how health professionals can assist them but rather how particular health professionals think they can serve consumers (Lunt). Although Lunt is referring to recovery from mental illness there are parallels for the recovery and rehabilitation process after a heart attack.

When the women in this study experienced symptoms of a heart attack they realised that something was wrong. When their heart attack symptoms subsided these women did not appear to view the healing of their body in the same way as health care professionals did. Some participants did not feel as though they even needed to 'recover'.

"I don't feel as though I was in recovery at any stage. The fact that I smoke, again I didn't smoke while I was in there, that was probably the longest in my whole life or since I was 18 that I hadn't smoked. But the 'recovery' I have never ever felt as though I was in recovery so that is a tricky one!"

(Rosie, 1:106-111)

For people who have suffered from a heart attack there must be some degree of physical healing. It takes approximately six weeks for scar tissue in the myocardium to become strong enough for strenuous exercise (Silverstone, 2000). Therefore it is important for the individual's physical recovery that they rest in the first six weeks after their heart attack. However this physical recovery is not the only aspect of recovery that needs to take place. Recovery also has psychological and emotional components (Kellmann, 2002).

Generally when symptoms subsided and participants began to feel well they did not see the need to continue with medical interventions and intrusions. The difference in views related to recovery may occur because health professionals view recovery as an extension of the acute phase of the heart attack. As a result the expectations of what people will gain from cardiac rehabilitation may be one sided and almost solely related to aspects that health professionals believe are important, such as making lifestyle changes to prevent recurrence. Lawler (1991) suggests that when nurses believe a patient is capable of recovery they maintain control over what the person is expected to do. In return the patient is expected to comply with the nurse's expectations (Lawler).

In the available literature the terms 'recovery' and 'healing' are used almost interchangeably while at the same time being used to describe slightly different aspects of the same process. According to The Pocket Oxford Dictionary (Thompson, 1992, p. 405) the word 'heal' is defined as "to become sound or healthy again". Healing involves the

body returning to functioning through the repair of cells and structures within the body. Healing is also used in the literature to describe returning to emotional or spiritual well-being. Healing is referred to in the literature as either healing physically (Pediani, 2001), or as healing on a spiritual or emotional level (Smith, 2001). It is clear from this that healing is used to define both physical and non-physical occurrences (Glaister, 2001).

This is significant because cardiac rehabilitation programmes have been set up using the perspective of health professionals rather than the perspective of the person experiencing recovery from a heart attack. When the heart attack is acute, health professionals consider they should be responsible for the well-being of the individual. Treatment is given and particular changes in behaviour, such as not smoking, low salt intake and rest are expected. When the heart attack is less acute and the individual is discharged from hospital, responsibility for health is pushed back onto the individual (Crooks, 2001). Cardiac rehabilitation programmes attempt to do this by the provision of information about the heart and ways to reduce cardiac risk factors.

Until July 2002, cardiac rehabilitation in New Zealand was based largely on overseas guidelines and everyone went through the same type of rehabilitation process (AHF, 2000; WHO, 1993). In July 2002 New Zealand guidelines for cardiac rehabilitation were released. Variations in the programme are made depending on the health care professionals involved, but generally people are told that a heart attack is serious and that because they have suffered one, they need to make changes to their lifestyle. This may be at odds with what actually happens when they return home. For example, people are told to make dietary changes but when they get home they are responsible for preparing food for others who may not want to make those dietary changes. This makes it harder to modify lifestyle.

“My daughter rang up said ‘mum I need to lose weight but I can't do it and it wouldn't hurt you either’ and I said ‘no’ so we are going to Weight Watchers, which is...yeah a lot better. But when you have got somebody in the house that likes their sausages, eggs and chips and things like that, it makes it very difficult”.

(Beth, 1:89-93)

Lifestyle changes were also forced by having the diagnosis of a heart attack. Rosie found the diagnosis of a heart attack affected the way she felt about activities she had previously engaged in happily. Despite feeling well she found the label of a heart attack inhibiting.

“I find that I am actually inhibited because they always ask you know ‘do you have’ and there is no way that I would put the responsibility on them, so I am very very honest, I won't dive, I would scuba if I were away and things like that”.

(Rosie, 1:291-293)

Not all of the women in this study attended phase two cardiac rehabilitation. At the time of interview two participants had not attended any phase two cardiac rehabilitation, three had attended some but not all sessions, and four had attended all available sessions (refer to table 11). The most common reasons for not attending were related to work and family commitments and transport difficulties. The low attendance rates of women at cardiac rehabilitation programmes has been well documented (Everson, et al., 1998; Halm et al., 1999; Parks et al., 2000; Wallwork, 1996). Many women may simply make the choice not to attend because they do not feel that they would benefit from the programme. They may feel that they have enough information, as was the case with several of the women in this study.

Although choosing not to attend cardiac rehabilitation is not seen as a problem by some individuals, health professionals may view it as problematic. When individuals do not attend cardiac rehabilitation health care professionals are unable to exert the same pressure to change and have less control over the individual. Not attending cardiac rehabilitation is, however, a problem for individuals who want to attend but for a variety of reasons are unable to. Transport may be an issue, particularly for those who live alone or have dependent spouses. During the initial six-week recovery period people are advised not to drive. Not being able to drive means having to rely on other people for transport and not everyone has this sort of support.

Transport was an important issue for some of the participants in this study:

“Well they suggested of course that I go into this town but I couldn’t see the point really. Struggling to get into town on a (mobility) scooter and some of these places are upstairs which cuts them out entirely for me”.

(Elizabeth, 1: 66-68)

“I only went to that (cardiac rehabilitation programme) about four times because I haven’t got a car and transport was a problem”.

(Ruth, 1:31-33)

Pressure to return to work (both from self and from the work place) may also limit access to cardiac rehabilitation sessions.

“Now for me to be off work would be a really stressful situation for me. I would probably be doing an awful lot of physical things as opposed to mental things, which I do at work...Realistically I didn’t feel I would benefit from being at home”.

(Rosie, 1:61-64)

“The fact that I work up here isn't a great deal of help but I am going to try, work permitting to take Wednesdays off, and that's...that's the day they had the meetings here, and certainly go to the next one at least and then I'll see, I'll see how I feel about it, you know, whether I think it is worthwhile to go again or whether it's not”.

(Margaret, 1:173-178)

Needing to spend time with family and do things for others also contributed to non-attendance.

“I hadn’t, I haven’t actually been to rehabilitation meetings. I would like to, um...circumstances have sort of conspired against me one way and another, I have had people, you know my daughter was staying with me and she came from (city) because I gave her a fright”.

(Margaret, 1:107-111)

Because recovery is a self-determined process it is affected by the individual’s perception and self-awareness (Kellmann, 2002). Therefore rather than being controlled by the health professional’s view of recovery it should be controlled by the individual’s view. This means that aspects of life that are important to women, such as work and family, need to be incorporated into recovery strategies. In this way women would not miss out on cardiac rehabilitation but may instead have it delivered in a more appropriate way.

Restricted Roles

For some of the women in this study recovery was characterised by not being allowed or able to perform their usual household or family roles. Some participants in this study became frustrated and even angry because they were told that they could not perform the everyday tasks that they were used to doing. This created conflict for both their work commitments and family commitments and is intrinsically linked to their social roles. This frustration was evident during interviews with Beth.

“I mean they told me to rest, try and not do anything, I mean I thought oh, I feel quite good, so I got up and made some mushroom soup and (CR nurse) happened to arrive and she went berserk. I am not even supposed to be doing that! So, but I felt that I was only just standing there making (soup), I felt like doing something.”

(Beth, 2:334-338)

Not carrying on with daily activities was mentally stressful for participants and being unable to do things for themselves was particularly difficult for participants who did not want to be a burden on their families. This was a huge issue for Beth:

“That really got to me, sitting and not being able to do anything... I often thought I would have been better up doing little bits than just sitting and doing nothing... like preparing the vegetables for tea, I couldn't see that that would be anything stressful or hard but she said ‘yes it is, you have got to rest your heart completely’. I don't know whether other people feel that they want to get up and go and do things...no, I think that was the hardest, of having somebody do everything for me when you are not used to it, you know, you are sort of sitting there, or seeing things that needed to be done and I didn't like saying ‘well, can you do this’ or ‘will you do that’ it is driving me, you know, and I would want to get up and do it and think ‘well, if I do’ but it doesn't matter what I do if I get up and do it I could be doing some harm if I don't but if I sit here I am still getting stressed out, what do you do?”

(Beth, 1:72-83)

Not only was Beth frustrated by being told she couldn't do what she wanted to, her husband was annoyed about it as well, and this seemed to add to the frustration and stress caused by the situation Beth found herself in. For Beth the standard approach to recovery and rehabilitation after her heart attack caused extra stress and made it even more difficult to cope with what was happening to her. Hart (1998, p. 1182) suggests health “professionals need to attend both to the practical/physical ‘doing’ aspects of rehabilitation, and the social-psychological aspects of ‘being’”. Therefore health professionals need to pay attention both to the physical restrictions they impose on people and to the effect that this has on the individual.

Kellmann (2002, p. 7) suggests that recovery, in relation to sports related injury, is achieved through “an enhancement of activity (e.g., physical exercise), a reduction of activity (e.g., sleep), or a change of activity (e.g., circuit training)”. Therefore recovery is dependent on a change, reduction, or break in stress. This implies that recovery does not

need to involve total rest and that recovery can be enhanced by alternating types of activities so that when the body is working the mind can rest and vice versa. Although Kellmann is discussing recovery from a sports perspective this is a concept that has relevance for people recovering from a heart attack.

Recovery is closely linked to social and situational factors (Kellmann, 2002). It is easy for health professionals to tell people what they should or shouldn't do. However it may be difficult or even impossible for the individual to do what they are asked. Rosie provides an example of this:

"You know, I do watch but he tends to always, we probably have had a roast most nights of the week which might be more typical for our age bracket but if he is frying up anything, he would fry up leftovers and things like that and I used to initially say to him 'please don't use butter, use oil or something like that' but he doesn't like the flavour of oil so now I would rather heat in the microwave, reheat something than have it fried".

(Rosie, 1:132-137)

For Rosie making dietary changes was not easy because her husband often did the food preparation and liked his food cooked in particular ways. Rosie managed to overcome this by cooking her food separately, however some women may find this more difficult to achieve because of the expectations of their families. Research into the barriers experienced by cardiac patients in relation to making dietary changes identified family eating habits as a constraint, as family members did not want to change their eating habits (Koikkalainen, Lappalainen, & Mykkanen, 1996). It is easier to make lifestyle changes when family support those changes (Frenn et al., 1989).

Different people have different recovery needs therefore recovery strategies must be individualised, so that people are able to choose the strategy they feel comfortable with (Kellmann, 2002). Social and personal factors should be taken into account when planning these strategies, including work both inside and outside the home, as well as the individual's social and family needs. Hart (1998) found conflict between the patient's goals of recovery and the health professional's goals of rehabilitation. Hart suggests that

the challenge for health professionals is to find a balance between providing support for recovery without intruding into the private lives of the people they are dealing with.

Summary and Conclusion

Finding a cause for their heart attack was an important part of coming to terms with having a heart attack and a necessary part of the recovery process for the women in this study. However, 'recovery' itself was not a clear-cut process, instead there are two perspectives of recovery apparent in the data. The first is the focus of the women on 'living with' rather than on 'recovery' from the heart attack. This involved identifying a cause, getting on with life and accepting that the heart attack is just a part of themselves. Attendance at cardiac rehabilitation sessions was influenced by the individual's perceptions of recovery, the importance they placed on attending, and their ability to attend including transport issues.

The second perspective is that of the health professionals. This perspective is related to recognition of symptoms, treatment, recovery, rehabilitation and prevention of recurrence. It is a very medicalised perspective that has a tendency to blame sufferers for not recognising and acting on symptoms and for not making the recommended changes to lifestyle. These perspectives follow the heart attack sufferer through initial symptoms to rehabilitation and recovery. Having a heart attack resulted in disruption to lifestyle. The following chapter discusses data related to the disruptions of their lives and how they acted to regain aspects of their lives that were important to them.

Chapter 5

Regaining Everydayness

Introduction

The previous two results chapters have discussed categories related to symptom significance and recovery. This chapter explores the core category found in the data. According to Glaser (1978) a core category is one that is central, recurs frequently, relates meaningfully to the other categories, has clear and grabbing implications for theory, is variable and does not lead to a dead end. The core category found in the data is that of 'regaining everydayness'.

A heart attack caused disruption to the everyday lives and functioning of the women in this study and their recovery involved striving to regain the social roles and responsibilities they had before. The women in this study strove to 'regain everydayness' despite many experiencing other illnesses. Being supported by those around them was an important part of this struggle. This chapter discusses how everydayness was disrupted and whether or not cardiac rehabilitation contributed to 'regaining everydayness'.

Disruption of Everydayness

Suffering a heart attack resulted in different degrees of disruption to the lives of these women. The degree of disruption experienced depended on the significance their symptoms held for them. The experience of a heart attack took participants out of their normal environments, disrupting their activities and routines. Being in a strange environment rather than a familiar one decreased the control that some participants had over their situation. This, combined with a lack of information, resulted in feeling out of control and removed from 'everydayness'. The degree of disruption depended largely on the significance their symptoms held for them. Participants who did not perceive they were ill, such as Rosie, managed to maintain control over their situation. Those who were

less sure of a positive outcome, such as Beth, did not have the same sense of control over what was happening to them. Having a sense of personal control has been linked to positive outcomes for patients (Bohachick, Taylor, Sereika, Reeder, & Anton, 2002). Moser and Dracup (1995) found that people with feelings of 'high control' exhibited less anxiety, depression and hostility than those with feelings of 'low control' after a cardiac event.

Despite feeling supported and cared for, many of the women in this study clearly felt a lack of control when they were in hospital. This lack of control was accentuated by a lack of information about what was happening to them and what to expect.

"And they sent me for a test. And nobody had explained what that was all about. Just told me I was going over for a test, they just said 'no, we are going to have a look' ...now I am very claustrophobic and they put me under this machine and I just got hotter and hotter and hotter but if I hadn't had my hands up, I would have panicked real bad".

(Beth, 1: 160-165)

For most participants, feelings of control improved when they returned home. However being told what they could and couldn't do around the home reduced these feelings of control. For those participants who found the hospital environment very safe and supportive, being discharged home caused feelings of anxiety at having to take control.

"I was quite shocked when doctor (name) said 'no you can't have a shower yet, you are on bed rest' nobody had ever told me I was on bed rest, I just did what I wanted. I wandered around a bit you know, because I never really felt fragile until after I came out and I think that might have been because my support had gone".

(Nicola, 1:2, 34-38)

Some participants simply felt 'ordinary'. Feeling ordinary made 'regaining everydayness' easy for these women from the point of view of returning to their normal level of functioning.

"I never really noticed any difficulty in anything, no, I go for walks up and down here now and again but I don't feel breathless or anything, I just feel ordinary, how I used to feel".

(Kathy, 1:59-61)

However, 'feeling ordinary' made it more difficult for participants to acknowledge and deal with the fact that they had suffered a heart attack, and this in turn made them less likely to choose to attend the phase two cardiac rehabilitation programmes available.

Although the symptoms experienced were not part of ordinary everyday life, they were used by some participants as a reason for altering routines and roles. Each participant responded in an individual way because of the unique significance of their symptoms. For example, Nicola used aspects of her recovery to alter her daily habits in a way that provided a positive outcome for her.

"It was quite nice where ...I could say 'no I don't want to do that today' and I, because of the diabetes I had had to watch what I ate anyhow, so it hasn't made much difference to the food but it has made, I have gone to bed much earlier, I rest quite a lot and I really quite enjoy it".

(Nicola, 1:1, 103-107)

Nicola also continued to attend the cardiac rehabilitation sessions after she had completed all of the phase two programme. Participating in cardiac rehabilitation sessions became part of 'everydayness' for Nicola. She incorporated this help into her life and seemed to benefit from the social contact it gave her. Nicola also incorporated some of the information she was given about resting and felt able to make decisions about her life. For example, she felt that she can say no:

"I can say 'no'. That was a very important one, that I had an excuse to say no".

(Nicola, 1:1, 102-103)

For some participants 'everydayness' was adversely affected by continuing health problems, which could be attributed to their heart attack or its treatment, including repeated episodes of pain and other related symptoms. Continuing episodes of pain were not only disruptive to everyday functioning, the resulting insecurity about the future caused a great deal of distress. Despite this, participants such as Beth continued to try and regain 'everydayness'.

A common theme was 'just trying to get on with it' (life):

"I supposed it was just a matter of thinking oh you know I've got to get cracking, got to get you know... do things, I can't sit around here".

(Beth, 1:187-188)

Family members also seemed to expect a rapid return to everydayness. When this rapid return was not achieved it was seen as being the fault of the sufferer. As a result the woman was judged as not having tried hard enough and blamed for her slow recovery. This is supported by the following comment made to Beth by a member of her family:

"But he just said to me...you know... 'you've just got to buck up' he said, he said 'mine was 15 years ago and I am ok' and I said 'I know but'...".

(Beth, 1:308-310)

Adapting to changes in health is part of the recovery process. In this sense recovery did not necessarily mean regaining health but rather it involved adapting to continuing health problems. It is apparent that, for some women, continuing health problems related to their heart attack, such as chest pain or angina attacks, eventually became part of the individual's 'everydayness', and adjustments were made to everyday life that enhanced coping. This means that rather than actually 'getting over' them the health problems simply became an everyday occurrence. For Beth this meant carrying Nitrolingual spray and learning how to use it to prevent and treat her recurring episodes of pain.

"If I go anywhere, I go to the girls college to do this computer class, and I put it in my pocket and you think just in case because you have got a lot of stairs to climb, so, but it does, it bugs me and I think oh, if we are going anywhere, have I got these things with me. A couple of times we have had to come home because I haven't taken my bag".

(Beth, 2:188-192)

For women who did not have recurring health problems regaining everydayness was not problematic and they seemed to fall back, with apparent ease, into the pattern of life they had before. However this also made it more difficult for these women to believe that they had really suffered a heart attack.

"I did everything I normally did except change my diet and walk but physically I always felt as though I was extremely fit, nothing was ever a burden for me".

(Rosie, 1:112-113)

In Sutherland and Jensen's (2000) study of women's perceptions of suffering a heart attack, they found that a process of change occurred. A change process also occurred for the participants in this study. 'Regaining everydayness' involved reframing everydayness in order to make their experience of a heart attack fit with their lives.

Coping With Other Illnesses

Other health problems also disrupted the return to 'everydayness'. Several of the participants in this study experienced colds, bouts of influenza, and musculoskeletal problems, which often appeared to be more disruptive to 'everydayness' than the heart attack they suffered, as Julie illustrates:

"It has been far worse than the heart attack. There is a pain in my neck, up there, and into my shoulder and then just recently I couldn't use my arm for about a week".

(Julie, 1: 45-47)

These health problems also made it difficult to follow the rehabilitation programme they had been given.

"I basically haven't had an exercise programme because my leg has been so sore, it is still sore to touch and when I walk it feels as if I have got a big lump of flesh hanging down, because it is sort of that numb funny feeling. It's a weird feeling".

(Margaret, 1:121-125)

In Margaret's case the problem with her leg was a direct result of the treatment she had received for her heart attack, and meant she was unable to participate in the prescribed exercise regime. It was apparent that no attempt was made to modify the programme for Margaret so that she could participate.

Even a relatively common illness such as influenza caused a delay in ‘regaining everydayness’. Beth provides an example of this:

“I got the flu and then I really couldn’t breathe properly and went to the doctor and they put me on the nebuliser and I ended up in hospital for another week with acute asthma. Never had asthma before and started back at the rehabilitation, then I ended up back in hospital with another dose of asthma”.

(Beth, 1:51-55)

In contrast to this, chronic illnesses did not seem to disrupt the process of ‘regaining everydayness’. Instead they were part of that ‘everydayness’ and were more often viewed as an annoyance. This was particularly obvious for those participants with significantly decreased mobility, such as Elizabeth who had arthritis in her hip joints, Rachael, who suffered from Parkinsons disease, and Kathy who had rheumatism and diabetes.

“But it is all my things that I have got wrong with me, and the thing is, I don’t really feel ill, I don’t feel that I have got anything wrong with me, it is just these, you know the rheumatism that is the worst, it is a real nuisance really”.

(Kathy, 1:169-172)

Women who have heart attacks are generally older and have been reported to have more chronic illnesses, such as arthritis, diabetes, and hypertension, than men (Cannistra et al., 1992; Conn et al., 1991; Loose & Fernhall, 1995; Schuster & Waldron, 1991). However having a chronic illness did not necessarily mean that recovery was more difficult. For some participants having a chronic illness seemed to aid their recovery.

This certainly seemed to be the case for Ruth:

“I think I was better to...well, being an asthmatic all your life sort of do tend to put things to one side and carry on with life and accept it as it comes, you don't sort of sit back and think about things, not like you know, a lot of people do, some people you wouldn't dare ask them how they are because they will tell you in great detail”.

(Ruth, 1:87-91)

For many participants the negative aspects of other health problems impacted significantly on the perceptions of their illness and recovery. For them having a heart attack was simply a minor ‘loss of time’ following which they returned to their life as it had been before. The effect of both acute and chronic illness on ‘regaining everydayness’ was individual and related to the significance placed on the heart attack and its associated symptoms by the woman concerned.

Carrying On

‘Regaining everydayness’ also involved participants returning to work. For some women this meant returning to paid employment and for others it was returning to running their household. Hamilton and Seidman (1993) investigated women’s return to work following a heart attack and found that within four weeks, three quarters of the women who participated had returned to normal household duties. The ability to return to work was also related to the significance participants attributed to the heart attack.

“I felt as though I should not have been in hospital, but they did keep me in there a week and I got lots of work brought up for me to do and I was totally bored and came out and went straight back to work”.

(Rosie, 1:43-46)

Participants with dependent spouses tended to return to work much more quickly. They appeared to fall back into the role of caregiver as soon as they came home from hospital.

Rachel provides an example of this in the following discussion:

“Oh I don’t think so. I um...my husband wasn’t good because he had had a stroke two years before”.

“So were you actually caring for him at that time”?

“Yes (...)”.

(Rachel, 1:113-119)

Elizabeth provides another example of this:

“I have got a very sick husband (...) he has lost his hearing, his sight, his sense of taste and he is not really with us at times, I have got to do all the thinking for him and see to everything so I have a fair old burden on my shoulders”.

(Elizabeth, 1:19-26)

Participants in this study who had dependent spouses did not receive the same pressure about the need to rest from the cardiac rehabilitation nurses as those whose spouses were independent. This may have been because the cardiac rehabilitation nurses recognised that a decreased level of activity would have been difficult for them to achieve, as there was no one to do this work for them. As a result of this, these women resumed most of their normal activities as soon as they returned home from hospital and therefore did not have the recommended six weeks of rest to allow their heart muscle to heal.

Returning to household duties was very important for all the women in this study. Previous research has identified that older women felt they needed to get back to their previous level of functioning (Murray et al., 2000). King (2000) investigated the return to normal functioning of women after cardiac surgery, and found women returned to the traditional roles of housekeeping and care-giving before they considered they had returned to their normal level of activity. It has also been suggested that ‘work’ needs to be redefined to include or incorporate women’s roles within the home and family. This would

make women's return to work more obvious and therefore make it easier to see the effects of women returning to work (King).

'Carrying on' was something that all of the women in this study attempted to do. It appears that as women they were expected by others to carry on and expected themselves to be able to cope with all of the aspects of daily life they had dealt with before their heart attack. For them it was not a case of learning to live with the heart attack but rather a case of fitting their heart attack into their usual roles and responsibilities.

Being Supported

'Regaining everydayness' was facilitated by support. In most instances participants felt that they were supported and encouraged during their recovery. Support came from a range of sources including family, friends and other social contacts and included physical, social and emotional support. Moore (1996) examined the perceptions and experiences of women participating in a phase two cardiac rehabilitation programme. She found that the women in her study received some of their support from health professionals, but this did not include emotional support, however family, friends and church associates were seen as major providers of social support. Being supported included having friends and family who were willing to provide the types of assistance required by participants. Nicola provides an example of the type of support she appreciated receiving:

"My friends were always there to take me hither and yon. For the first couple of weeks or so my meal was brought over to me here and I could get a reduced fare on the taxi when I, because I couldn't drive and one of the things that I found most helpful to my recovery was when I went back to church! I got such a welcome. You know, and they said 'oh how nice to see you', you know, 'I hope you are feeling better' so I think it was just the caring of people".

(Nicola, 1:62-69)

For the women in this study being supported also involved assistance from health professionals in the form of education and information about what had happened to them. Giving information is part of the nurse's role in any clinical setting. Some participants

commented that the health professionals they dealt with while they were in hospital were caring. Participants perceived health professionals as 'caring' when they appeared able to spend time talking to them, as well as when their physical needs were met. A caring relationship with health professionals encouraged feelings of trust, which in turn enabled the individual to make use of the help and information offered.

"I thought they were marvellous at the hospital, you know, I had a lot of injections and they always told you what it was for or they would say 'do you know what this is for?' and sort of kept us, sort of gave us lots of information about what they were doing and why they were doing it, and I thought they were great. I couldn't have faulted any of them. They were really good".

(Julie, 1:121-125)

The emotional and physical support given by nurses in the early stages after a heart attack provided participants with feelings of safety and security about their well-being while in hospital.

"They (nurses) were all very cheerful and easy going and a relaxed atmosphere, but they all seemed to really know what they were doing... Made you feel safe. Really very caring. Like, I wasn't allowed to get up to the toilet or what not and when I did, they came with me and told me to go slowly, which I have never been good at".

(Julie, 1:189-194)

Perceiving health professionals as caring encouraged participants to ask questions and gain some of the additional support and information participants felt they needed.

“I felt it was good because you could talk to people who have had heart attacks and people starting coming in that I knew and (CR nurse) was always available to talk to and the doctor used to come in sometime and we could talk to him and you didn’t feel so alone, that was one of the things and I have made a couple of friends there and it was just a really satisfying experience and because of that I have gone back”.

(Nicola, 1:84-90)

However, if participants did not feel comfortable about the health professional’s level of caring or perceived that nurses were very busy, they did not seek the information they needed. This meant that their needs for information were not always met. Several participants did not realise they had received phase one cardiac rehabilitation and some participants felt as if they were discharged without any real support from health professionals.

“You are just sort of discharged and ‘somebody will come and see you’ and that is it”.

(Beth, 2: 264-265)

Although most nurses were perceived as being caring, the cardiac rehabilitation nurses were seen as being more approachable and supportive for recovery. There was a general perception among participants that the cardiac rehabilitation nurses had more time to spend with them once they had been discharged. As a result of this participants seemed more prepared to seek information from the cardiac rehabilitation nurses than from the other health professionals they encountered.

“The nursing staff are very very good in the Coronary Care Unit but they are very busy and I tend not to ask lots of questions because you don’t, you don’t sort of want to hold them up. I mean they were friendly and if I needed information, they would give it to me but I...I found talking to her (CR nurse) was easier in that she had come specifically to see me, to talk about being rehabilitated”.

(Margaret, 1:69-75)

Participants who needed to return to their previous roles rapidly, such as those with dependent spouses, appeared to do so with or without the support of the cardiac rehabilitation nurses. Some of these women received support in the form of home help, however this did not relieve them of many of their care giving responsibilities. Instead home help gave them assistance with cleaning, laundry and other household tasks. Care of their dependent spouse was still the responsibility of the women themselves unless other family members were able to fill this role.

The participants in this study were obtained through two different cardiac rehabilitation programmes. Participants were invited to attend phase two cardiac rehabilitation sessions related to the following topics: managing emotional responses to a heart attack; nutrition and healthy eating; understanding medications, stress and time management, exercise; CPR instruction and information on what to do in an emergency; and understanding how the heart works and what heart disease is. Actual content varied between the two programmes.

Tables 11 and 12 provide an overview of the cardiac rehabilitation received and the participants’ interpretation of the reasons for not receiving or attending cardiac rehabilitation. There was a noticeable difference in the amount and type of support each woman was offered by the cardiac rehabilitation nurses, but this support did not appear to be related to individual needs. For example Elizabeth was not offered a lot of support despite being in a wheel chair and also having a husband who, though physically able, required supervision and assistance with many everyday tasks. The support offered by cardiac rehabilitation nurses included home visits, information about the phase two programmes, and assistance with transport for some participants. It is interesting to note

that over half of these women were not aware they had received any phase one cardiac rehabilitation while in the hospital setting.

Table 11: Cardiac Rehabilitation Received by Programme One Participants

Participants	Phase One	Home Visit	Phase Two Attendance:
Nicola	Not mentioned	Yes	All
Beth	Yes - was seen by CR nurse	Yes (2 or 3 times)	All
Rosie	Yes – specifically remembered exercise information	Not mentioned	All except two – psychologists session and supermarket tour
Elizabeth	Yes - prior to discharge	No	None –Didn't think she could gain access (wheel chair)
Ruth	Not mentioned	Not mentioned	Four sessions –transport problem
Kathy	Not mentioned	No Lived out of town	Some –exact number not mentioned
Rachel	Not mentioned	Yes (3 times)	All

Table 12: Cardiac Rehabilitation Received by Programme Two Participants

Participants	Phase One	Home Visit	Phase Two Attendance:
Margaret	Very little	Yes - 1	None – due to work and family commitments
Julie	Not mentioned	No –didn't feel it was necessary	All –found them helpful and interesting
Dorothy	Not mentioned	No - second heart attack	All – found some uninteresting

Although the women in this study received advice and information on making lifestyle changes, such as advice about exercise, diet and giving up smoking, it appears health professionals did not provide education about how such changes could be managed. Helpard and Meagher-Stewart (1998) found that rules laid down by health professionals during the period of convalescence following a heart attack, were not always congruent with the women's role perceptions. According to Helpard and Meagher-Stewart this type of conflict resulted in "bending the rules" (p. 19). This was also the case for some of the

women in this study. However those who did not ‘bend the rules’ experienced feelings of frustration and anger at the restrictions placed on them.

It seems that although cardiac rehabilitation programmes provide information, social support is not always a priority. Moore (1996) found that the women desired more emotional support and social interactions. In a study examining the meaning that elderly women with coronary artery disease attach to their illness, social support was found to be important, particularly emotional support (Helpard & Meagher-Stewart, 1998). Social support has been shown to improve the outcome for people who suffer from cardiovascular disease. People who perceive they have social support have been shown to exhibit less cardiovascular reactivity (Craig, Lynch, & Quartner, 2000). This indicates positive physiological benefits to providing adequate social support.

One aspect of support that participants found lacking was peer support. For these women it was important to feel as if they fitted in with others in the cardiac rehabilitation group. Being able to relate to the experiences of those around them made them feel as if they were not alone. However, in general this did not happen as most participants felt that there was no one else in quite the same situation as themselves. As a result, feelings of being isolated were common among participants.

“I just thought it would be nice talking to someone in the same boat as I was but there wasn’t, you know, as I said they have all had bypasses and angiograms and pacemakers, nobody was in my boat”.

(Beth, 2:18-20)

Rosie felt she was different because she hadn’t experienced any pain with her heart attack.

“No, there is no one like me. I mean I think too that the majority of them got such a fright with their heart attacks. I mean I wish that I had had pain. I wish that my pain had been so severe that it would have jolted me out of smoking”.

(Rosie, 1:161-163)

However, feeling different did not interfere with Rosie regaining everydayness. For other participants, particularly Beth, not feeling as if they fitted in meant they did not feel supported and this made it harder to reframe or regain everydayness.

Summary and Conclusion

The basic social process of 'regaining everydayness' involved participants adapting and adjusting to a life that incorporated their knowledge of suffering a heart attack as well as changes to lifestyle. For some women this was a relatively easy process. They were able to make compromises between the expectations of health professionals and the needs of their daily roles and in order to 'carry on' with life and work as they had before. Having had a heart attack became part of their everydayness. For women with recurrent symptoms, everydayness was more difficult and required much more drastic changes to their previous lifestyle. These women did not regain the life that they had before their heart attack but instead 'everydayness' was reframed to incorporate continuing health problems.

Returning to work was very much a part of 'regaining everydayness' for these women. Work constituted a fulfilment of their normal social role and even if they were not supported to return to work they often did so anyway, as returning to care giving roles and household duties was frequently a priority. Although some types of support were present, many participants still felt isolated and unsupported. For some this was because they did not feel they had anything in common with other people attending the cardiac rehabilitation programme, while for others it was because their need to return to 'work' was not acknowledged by health professionals. Most participants felt they had received little or no phase one cardiac rehabilitation but felt that phase two programmes provided good informational support. Cardiac rehabilitation nurses were viewed as being more approachable and proved to be a useful source of support for most participants

Chapter 6

The Process of Reframing

Introduction

A basic social process is a type of core category or “central theme that unites all categories” and explains much of the variation found within the data (Schreiber & Stern 2001, p. 3). It is distinguished from other categories in that it is “processural” in nature. In other words it has more than one state of being, can change over time and embodies the actions of participants. It must have significant explanatory power or “grab” and the analysis should carry through rather than have a “dead end” (Schreiber & Stern, p.75). The basic social process present in the data gathered for this study is that of ‘reframing’.

As discussed in previous chapters, part of the process of recovery for the women involved in this study was returning to their homes and families, and resuming important aspects of their lives. This involved incorporating their heart attack into their everyday life and gaining support for this process. They achieved this through ‘reframing’ their lives to incorporate the experience of their heart attack. This chapter discusses how participants attempted to regain their ‘everydayness’ through the process of ‘reframing’ and how cardiac rehabilitation contributed to this process.

Reframing

Suffering a heart attack was a life altering experience for the participants in this study. ‘Reframing’ was the process of adjusting to this life-altering event. Participants began ‘reframing’ when they experienced symptoms and for some this process was still continuing three years later. ‘Reframing’ involved trying to match up their symptoms with a cause. When the cause did not match what their experience suggested they then had to reframe their perception of possible causes to include a heart attack. For participants who realised their symptoms were heart related this part of the process of ‘reframing’ was

quick and they were able to readily accept that they had suffered a heart attack. However for participants who thought their symptoms were caused by other things, this process took longer.

Participants who were unable to identify a cause had more difficulty 'reframing' their lives to incorporate the heart attack experience. Initial symptoms disrupted activities and later on, hospitalisation caused major disruption to their family and work roles. Participants looked for something to blame their heart attack on. Some blamed stress, others medication, smoking, or the activity they were engaged in at the time symptoms began. Finding a cause and then working out how the heart attack would affect their future lives was an important part of the process of 'reframing'.

'Reframing' also involved participants working through what recovery meant for each of them. For participants who did not feel that they had been particularly ill it was hard to accept that recovery was necessary. The fact that health professionals tended to view recovery in a different way caused confusion. Participants needed to reframe how they viewed recovery in order to incorporate their perceptions with the perspective held by health professionals. Often the participants were frustrated by the differences between their view of recovery and that of the health professional, and it took time to find the 'middle ground' and work out what activities they could and could not do.

Activities were reframed to accommodate perceptions of recovery and the management of continuing symptoms. According to the NZGG (2002b, p. 15) one of the aims of cardiac rehabilitation is to facilitate the individual's "return to a full and active life by enabling the development of their own resources". The restrictions in work role placed on participants by the cardiac rehabilitation programme did not necessarily achieve this. Restrictions that participants did not perceive as being of benefit to their recovery caused feelings of anger and frustration.

The feeling of being supported was important for the process of 'reframing'. Support was required in order to deal with other acute and chronic illnesses and to enable participants to continue their usual roles. Participants had to carry on with their lives and needed to incorporate acute and chronic symptoms into their 'everydayness' and support was

necessary to facilitate this. Some participants could not accept the support that they were offered because it was inappropriate for them and did not meet their needs. When this occurred they often did not feel as if they were receiving any support at all.

The process of 'reframing' was affected by their previous experiences of illness, knowledge of CHD symptoms and risk factors, information they received from health professionals, and how they viewed their own state of heart health. At times health professionals directed this 'reframing' by placing restrictions on participants daily living activities. Cardiac rehabilitation also contributed to the process of 'reframing' by providing information and guidelines for recovery.

A Continuum of Recovery

Glaser and Strauss (1967, p. 23) suggest that "in discovering a theory one generates conceptual categories and their properties from evidence; then the evidence from the category emerged is used to illustrate the concept". Constant comparative analysis of the data resulted in the emergence of the concept of reframing. The concept of reframing was then developed as a relevant theoretical abstraction about women's recovery after a heart attack. The experience of a heart attack was not a linear or smooth progression from symptoms, to diagnosis, to treatment, to recovery. Instead it was a process that began with the experience of symptoms, which caused disruption to life and routine, leaving these women struggling to regain the lives they had before.

Health and illness have traditionally been viewed as being dichotomous (Antonovsky, 1979). This implies that people within our society are viewed as either healthy or unhealthy, viewing those with disease as unhealthy and putting the focus onto the disease process. Antonovsky suggests that health and ill health should not be viewed as separate entities but viewed as a continuum with degrees of health or ill health. Therefore people are not necessarily completely well or completely ill, but rather somewhere in the middle. Recovery from a heart attack can also be viewed as a continuum.

Figure 1 represents a model for a continuum of recovery and shows the progression from symptom experience through to 'regaining everydayness'. In figure 1 the bent arrows indicate a state of fluctuation rather than a linear progression. Within these categories,

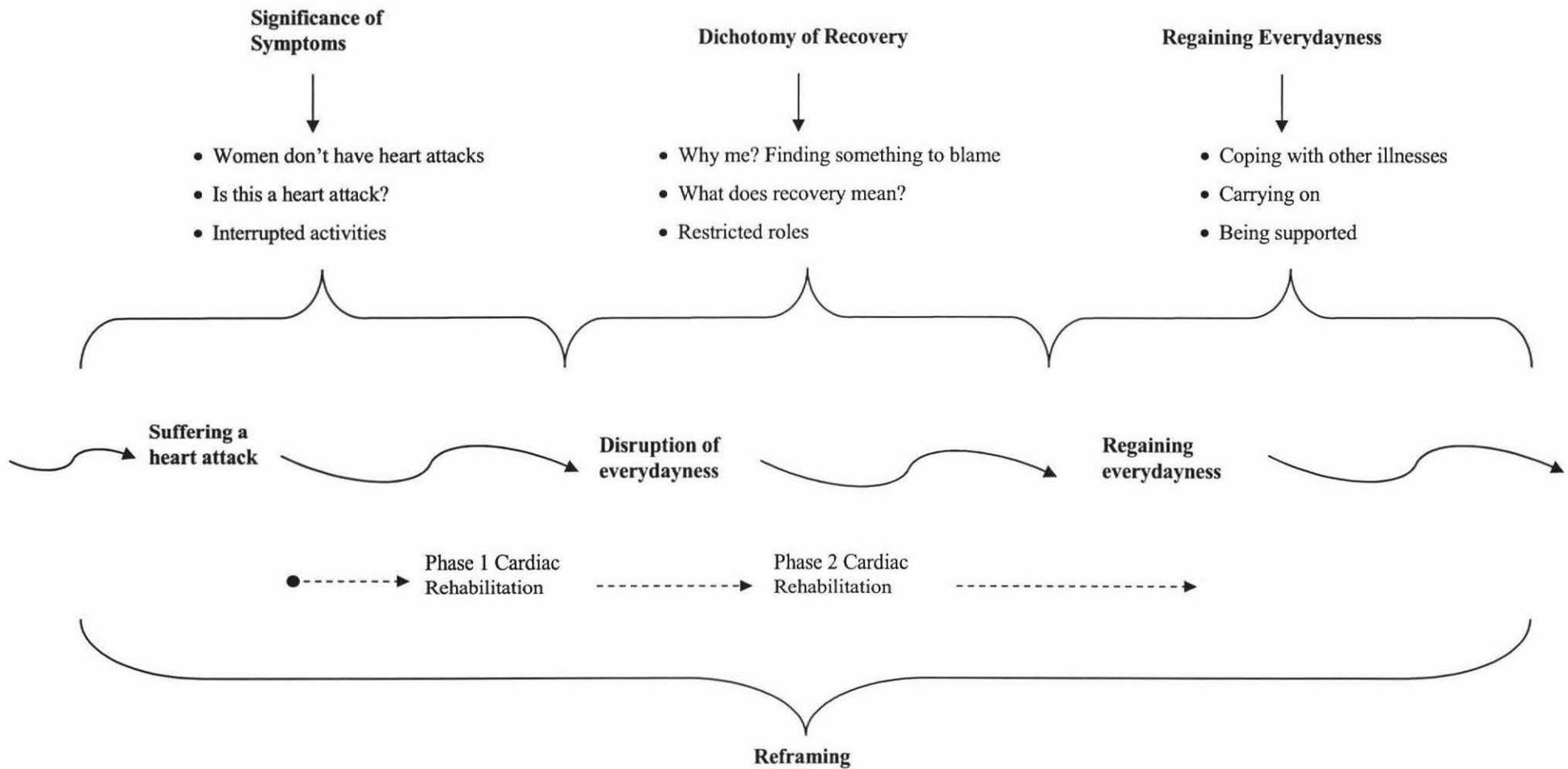
participants experienced different degrees of recovery ranging from not feeling ill and therefore not needing to recover, to continued symptoms and feeling as if they had made no significant progress toward full recovery. The broken arrows leading from cardiac rehabilitation indicate that it assisted some, but not all participants with the process of 'reframing'.

Disruption of 'everydayness' affected everyday roles and responsibilities in ways that were unique to each individual. In order to progress through the experience of suffering a heart attack, participants needed to know why they had suffered a heart attack and what it would mean to their lives. From the time symptoms were experienced women were trying to regain 'everydayness'. This meant incorporating their heart attack into their lives in a way that caused minimal disruption to their social roles. There is no clear timeframe for this continuum, however it is clear that it is not a short-term process because some participants had experienced their heart attack two or three years before being interviewed were still working towards 'regaining everydayness'.

The way that cardiac rehabilitation contributed to overall recovery varied for each participant, and was therefore not a constant or reliable assistance with recovery. Phase one cardiac rehabilitation began when the heart attack was diagnosed and was very subtle, many participants were not aware that they had actually received this phase. Phase two cardiac rehabilitation occurred when participants were trying to return to their lives and roles and for many it seemed to slow this return rather than assisting it. With or without cardiac rehabilitation all of these women 'recovered' to varying degrees.

The concept of reframing constitutes a substantive theory that is in the early stages of development. This theory requires further verification and testing not only on other women but also men who have experienced heart attacks. Further testing and development will lead to clarification of the concept of 'reframing' and the effects of cardiac rehabilitation programmes on the process of recovery after a heart attack.

Figure 1: Reframing: A Continuum of Recovery



Summary and Conclusion

The results of this study indicate that recovery exists as a continuum, which begins before symptoms are recognised and extends through to 'regaining everydayness'. Each participant went through a process of 'reframing', which occurred whether their heart attack caused minor or major disruption to their lives. 'Reframing' allowed most participants to fit their heart attack experience into their lives. The women who participated in this study identified different stages within this continuum. For some of them the process of 'regaining everydayness' involved returning to the life they had before their heart attack experience. For others it involved adapting to a new 'everydayness'. Recovery for these women was not something that was finished within the six to twelve weeks of the cardiac rehabilitation programme. Rather it was a process that continued for months to years and for some participants was still occurring.

Ensuring that cardiac rehabilitation programmes are equipped to assess and meet the needs of individual participants is a priority for health professionals. The final chapter of this thesis provides a discussion of, and conclusion about, the findings of this study and their application for the development of cardiac rehabilitation programmes.

Chapter 7

Discussion and Conclusion

Introduction

Grounded theory has been shown to be a useful research method for looking at social influences on women's health (Wuest, Merritt-Gray, Berman, & Ford-Gilboe, 2002). This study has used grounded theory in order to examine women's perceptions of the contribution of cardiac rehabilitation to their recovery from a heart attack. Perception of illness is central to the concept of recovery and this made it impossible to meaningfully examine the concept of recovery without first looking at the experience of suffering a heart attack. The purpose of this chapter is to provide a discussion of findings and relate these to current cardiac rehabilitation programmes. Also included are implications for practice and recommendations for future research.

Discussion of Categories

The basic social process of 'reframing' was central to the recovery process for the women in this study. The categories and subcategories that emerged from the data related to differences in their perception of recovery, symptom significance and alterations to usual life patterns. It is apparent from the data that the women who participated wanted to regain the 'everydayness' they had before their heart attack. Phase one and Phase two cardiac rehabilitation contributed to the recovery of participants by providing information about what had happened to them and what steps they could take to prevent another heart attack. It also provided social support for some participants.

The core category that emerged from the data was 'regaining everydayness'. In an effort to regain everydayness, these women reframed how they viewed their lives and their social roles. The participants in this study were at varying stages of recovery. Some had suffered heart attacks within the three months prior to being interviewed and they were still attending cardiac rehabilitation programmes. Others had experienced heart attacks as long as three years previously. For these women the recovery process was over as far as the health professionals were concerned but not as far as they were concerned. It is important to reinforce at this point that these women categorised themselves as having had a 'recent' heart attack. This indicates that the participant's view of the length of time taken to recover may be quite different to health professionals' perceptions of recovery.

For the participants in this study, suffering a heart attack caused feelings of surprise and shock. Despite symptoms being annoying enough to disrupt activities, they were not always significant enough that immediate medical assistance was sought. Interruption to activities was usually only temporary and symptoms were viewed as an annoyance rather than as an indication of serious illness. Research results suggest that women experience a wide range of symptoms that do not necessarily match the classic presentation of a heart attack (McSweeney, 1998; Penque et al., 1998). Symptoms and hospitalisation caused disruption to the everyday routines and role of participants. For some the disruption caused by continuing symptoms resulted in participants trying to 'reframe' their 'everydayness'. For others, this disruption was short term and resolved rapidly when they returned home so that the process of reframing occurred more easily. Crooks (2001) suggests that rather than just responding to events, women also take action and create solutions to life experiences through 'internal dialogue'. In this way women begin to adapt and adjust to their experiences of ill health.

Even though participants' experienced symptoms that could be linked to a heart attack, these symptoms were often attributed to other causes, such as indigestion or inhaling toxic substances, such as weedkiller. Participants had difficulty relating symptoms to a heart attack and therefore found it difficult to accept that diagnosis. Schoenberg, Peters and Drew (2003) suggest that the social construction of common symptoms is based on what is normal for men, negative encounters with health care providers, and the competing

social demands placed on women all affect their decisions to seek treatment for symptoms of CHD.

Differences in the use of language to describe symptoms may also have led to confusion over severity and cause. Jairath (1999) suggests that women use metaphors to reveal their underlying frame of experience and the meaning of that experience. This occurs even if health professionals impose their own framework on the individual. This may partially explain why symptoms often appear to hold different significance for sufferers and health professionals. It was also important for participants to feel they had something in common with other people who had experienced a heart attack.

Seeing themselves as 'typical' made it possible for participants to compare their experience with that of those around them. Women in this study who viewed themselves as not being typical had more difficulty adjusting to or believing they had suffered a heart attack. The significance symptoms held for participants had an influence on whether they felt they needed to recover, and some participants didn't perceive they had anything to recover from. The participants who did not feel that they needed to recover did not find phase two cardiac rehabilitation programmes particularly useful. These women tended to only attend the parts of the programme that they had decided would be of use to themselves.

The women in this study frequently asked "why me". Finding a cause for their heart attack was an important part of the process of 'reframing' for these women. Other research also suggests women want to find out why they suffered a heart attack. This search for meaning was related to the women's need to understand what had happened and what impact the heart attack would have on their lives in the future (Fleury, Sedikides, & Lunsford, 2001). The struggle to find meaning in the experience of a heart attack appears to be a necessary part of the recovery process. For most of the women in this study cardiac rehabilitation provided them with information on the possible causes for their illness. However, it did not seem to provide them with an environment in which they felt comfortable requesting more information or seeking clarification by asking specific questions.

The women in this study felt it was important to return to their roles, responsibilities and usual work. For them 'work' involved household duties and care giving responsibilities as well as employment outside the home. Research suggests that women are more likely to return to household activities sooner after discharge than men (Hamilton & Seidman, 1993), and that women are more concerned about not being able to fulfil their household role (Low, 1993). It was apparent that those participants with dependent spouses considered it necessary to return to 'work' more rapidly than those without. However they did not necessarily view this as being negative.

The women in this study had to find a balance between their usual roles and responsibilities, and the expectations of recovery and cardiac rehabilitation. This involved deciding what was most important for them and their families. This is supported by research investigating the role of 'self' in the experiences of women living with cardiovascular disease. This research found that women sought strength in everyday situations and redefined their personal and social priorities (Fleury et al., 2001). Research exploring the experiences of women survivors of heart attack found that the recovery process was initially characterised by fear and uncertainty. Over a period of time this was replaced with a more positive outlook, return of energy and a sense of confidence in the future over a period of time (Jackson et al., 2000). Fleury et al. (1995) discuss the concept of 'originating', in which women began to create new patterns for living, new expectations for themselves, and new ways of viewing the world. Men who have experienced a heart attack may also go through a process of reframing their everyday life (Arefjord et al., 1998).

Feelings of isolation were expressed by several participants, who felt they had nothing in common with the other people in their cardiac rehabilitation group. Fleury et al. (1995) found that women in their study sought meaningful connections with other people in order to obtain the emotional support they needed after a heart attack. The cardiac rehabilitation programmes attended by the participants in this study did not provide most participants with an opportunity for this kind of support.

Participants viewed social and emotional support as being important for their recovery. Literature suggests that women have higher levels of anxiety after a heart attack than men (Brezinka et al., 1998; Rankin, 1995; Schuster & Waldron, 1991) and therefore need more support. Health professionals in the hospital setting were generally seen as being caring but many participants felt the hospital staff were too busy to be approached. In contrast to this most participants felt that the cardiac rehabilitation nurses were very approachable and had time to answer their questions.

Although it is possible to look at the health or illness experience of either men or women in isolation from the social context they exist within, doing so encourages victim blaming and ignores any political, economic, or social constraints that women experience when seeking health care (Schoenberg et al., 2003). Women's health issues need to be investigated in a way that incorporates the experience of illness and social aspects of their lives in before the true impact of CHD on women can be understood. It is clear that social factors strongly influenced a participant's experience of a heart attack from the onset of symptoms through the recovery and rehabilitation process.

Cardiac Rehabilitation

Recovery was affected by participants' perceptions of their heart attacks. The symptoms they experienced were not what they expected and this contributed significantly to their failure to recognise the origin of those symptoms. Attendance at cardiac rehabilitation programmes was also affected by the perceived significance of their symptoms, the resulting need to recover, and the influence of social factors. As with other research, the barriers to phase two cardiac rehabilitation attendance included issues with transport, other health problems and obligations related to social role and responsibilities (Ades, Waldmann, McCann & Weaver, 1992; Lieberman et al., 1998; Parks et al., 2000).

Some participants did not attend all of the phase two cardiac rehabilitation sessions because other aspects of their lives took priority, such as family and work commitment, or because of problems with transport. Even though many of the participants in this study attended some or all of a cardiac rehabilitation programme, this does not necessarily mean that they participated in the programme in a way that contributed to their recovery, for example, were they able to ask the questions they wanted to.

Kellmann (2002) suggests recovery can be passive, active or proactive. Passive recovery involves rest and includes the autonomic psychological and biological processes that restore the normal or previous state of health. Passive recovery also involves medical treatments and alternative therapies such as relaxation. In proactive recovery a person is responsible for his or her own level of activity and decides when to initiate particular activities.

Current phase one cardiac rehabilitation programmes focus on early mobilisation (as per appendix 1) and information about heart disease so that sufferers can begin to understand what has happened to them (NZGG, 2002a; NZGG, 2002b). Most participants in this study did not think they had received any phase one cardiac rehabilitation. The absence of knowledge about this phase of cardiac rehabilitation may have been because the health professionals were too busy to supply the information adequately, or because it was provided too soon after the acute phase of their illness to understand and remember the material provided. However, it may also have been due to differences in the understanding of terminology, meaning they did not appreciate that the information they received and the mobilisation programme they went through while in hospital was part of the rehabilitation process.

“Very few people that I have interviewed have actually talked about getting information in hospital, phase 1”.

“No I didn’t, you know, there didn’t seem to, unless you asked questions and I thought ‘well I am not like that’, just wait for them to tell me what they think I should know”.

(Dorothy, 1: 124-128)

It was clear that participants did not ask many questions because they perceived the nursing staff as being too busy and not having time to spend with them. Therefore they did not always get the information they needed. Holroyd, Twinn and Shiu (2001) found that the interpersonal skills of nurses related to providing information, social support and counselling were highly valued by clients. However, the participants in this study were reluctant to ask nurses who appeared to be busy, for information and as a result their questions were left unasked.

During one of the interviews for this study a participant commented that she wished the cardiac rehabilitation nurse would communicate with her in the same way I was (sitting and talking in her lounge). This participant clearly wanted someone to sit down with her, in an environment that was comfortable for her, and answer her questions. It was obvious she had not felt able to do this at the cardiac rehabilitation group.

Women respond well to supportive environments in which they can talk to other women about their experiences. One way of adjusting cardiac rehabilitation to the needs of women may be to form support groups rather than having structured 'lecture type' sessions as currently done. Group sessions which encourage self-expression and connectedness can be used to help women cope with their stress (Bettencourt & Sheldon, 2001; Moore, 1996). Arnold (1997) suggests that group formats which offer essential social support opportunities for sharing experiences and to discuss information related to their heart attacks may be as important for women as any of the other parts of current cardiac rehabilitation.

The focus of phase two cardiac rehabilitation programmes is almost exclusively on modification of the lifestyle factors of the individual that are seen as being harmful (NHFNZ, 2000), and seeking to alter those risk factors. Hence the emphasis of current phase two cardiac rehabilitation programmes is not on recovery from the heart attack itself but on prevention of further cardiac events. However it is apparent that these programmes fail to provide strategies and support to help women make effective lifestyle changes possible. The meaning of 'work' also needs to be expanded to encompass household duties in relation to cardiac rehabilitation.

Although this emphasis on reduction of risk factors may assist in the prevention of further heart attacks it also has the potential to make people feel guilty and blame themselves for their illness. An approach emphasising the recovery needs of the individual would provide greater support for recovery as well as alteration in lifestyle factors for those who have risk factors needing modification. In a research study comparing the 'self-rated' health of women who had, or had not attended cardiac rehabilitation, findings showed that cardiac rehabilitation programmes were not adapted to women because they had no provision for emotional support in either the short or long term (Fridlund, 2000).

Phase two cardiac rehabilitation aims “to prevent further cardiovascular events by empowering people to initiate and maintain lifestyle changes; improve quality of life through the identification and treatment of psychological distress; and to facilitate the individuals return to a full and active life by enabling the development of their own resources” (NZGG, 2002a, p.2). It is assumed that to achieve adequate lifestyle change, women must attend a formal cardiac rehabilitation programme. However, women may be able to make changes that will benefit their heart health without attending such programmes (Fridlund, 2000).

Prior to the evidence-based best practice guidelines for cardiac rehabilitation being released in August 2002 there had been no national guidelines for cardiac rehabilitation programmes. The purpose of these new guidelines was to provide the most up to date information about cardiac rehabilitation and to make recommendations for care based on this information (NZGG, 2002b). It is interesting to note that despite women and heart disease being a current research priority for the NHFNZ women are hardly even mentioned in this document. Women are included in the section on specific populations, along with elderly, rural, and the socio-economically disadvantaged (NZGG). This section points out that women’s’ CHD has been under-researched and goes on to cite nine pieces of research related to women. None of the qualitative studies that are available and cited investigated the experience of suffering a heart attack or of participating in recovery and rehabilitation.

The best practice guidelines for cardiac rehabilitation (NZGG, 2002b, p.73) offers only one sentence solely related to women: “Women’s needs should be addressed in comprehensive cardiac rehabilitation programmes”, and provides no discussion about how this is to be achieved. The lack of information about how to meet the cardiac rehabilitation needs of women becomes even more surprising when examining the summary and resource kit, because it targets “all health providers working in cardiac rehabilitation in New Zealand, both in hospitals and in the community” (NZGG, 2002a, p. 1). This is the document offered to all health professionals providing cardiac rehabilitation. It appears that no health providers have been given adequate guidelines about how to address the needs of women, and therefore it is unlikely that specific needs are being meet. In order to

provide cardiac rehabilitation that meets the specific needs of women who have suffered a heart attack it is necessary to have an understanding of why behaviour change is necessary and how changing behaviour can enhance quality of life.

Participants generally felt positive about the phase two cardiac rehabilitation they had received, although these programmes did not meet all of their needs. Of particular concern was the lack of emotional support for recovery, and the lack of support for returning to their usual roles and responsibilities. Moore (1996) found that women wanted more emotional support from health professionals.

The women in this study went through a process of reframing, which involved recognising the significance of their symptoms, working out what recovery meant for them, and attempting to 'regain everydayness'. Cardiac rehabilitation contributed to this process by providing information about their illness and education on ways they could reduce their risk of further heart problems. Cardiac rehabilitation as provided did not meet all of the social, emotional and support needs of participants.

Models of Community Health Education

As well as investigating women's perceptions of recovery after a heart attack it is important that cardiac rehabilitation programmes are assessed for their effectiveness in relation to how and when information is provided. Models of health education have the potential to provide insight into different ways of providing people with information on health related topics. They have particular relevance for cardiac rehabilitation because these programmes aim to improve the participants' quality of life and prevent further heart problems through education (NZGG, 2002b).

One of the aims of cardiac rehabilitation is to reduce the risk of further cardiac events by encouraging people to change behaviours which put them at risk (WHO, 1993). Cardiac rehabilitation programmes are based on the assumption that participants are ready, able and willing to learn about the cause, risk factors and process of CHD. Several models of health education are discussed in the NZGG (2002b) guidelines for cardiac rehabilitation programmes, however their practical application in relation to the development cardiac rehabilitation programmes for particular groups, such as women, is not discussed. These

include the Health Belief Model, Self-efficacy Theory, Theory of Planned Behaviour and the Transtheoretical Model: Stages of Change. Although any of these models could be used as a basis for cardiac health education I believe two are of particular interest for the development of cardiac rehabilitation programmes in New Zealand.

The Stages of Change Model was developed by Prochaska and DiClemente (1984). According to this model “people do not usually change their behaviour suddenly, completely or permanently” (Baum, 1998, p. 304). Rather behavioural change is an ongoing process, which follows five stages. Individuals may move through these stages in sequence or may go backwards and forwards between the different stages.

The first stage is one of *precontemplation*, where there is no intention to change the behaviour. The second stage involves *contemplation* and making a decision whether or not to change. The third stage involves *preparing for behaviour change* in the near future, having experimented with behavioural change in the past. The fourth stage involves *action*. In this stage behaviour is successfully changed over a relatively short time. The fifth and final stage involves maintenance of the behaviour change over a longer period of time (Baum, 1998, p. 304). The developers of this model suggest that it is important for health care workers to recognise when people are in the precontemplative stage as behaviour change is unlikely at this stage (Baum).

If the Stages of Change Model was applied it would have important implications for cardiac rehabilitation programmes. As they currently stand, programmes are developed and run using a group format that fails to take into account the individual needs of participants. Also, because cardiac rehabilitation begins during the acute phase of a heart attack those attending may be only in the early stage or precontemplative stage of this model. If this is the case then the changes of behaviour aimed for by the rehabilitation programmes are unrealistic.

The Health Belief Model can also be applied to cardiac rehabilitation (NZGG, 2002b). This model was developed in the 1950s by social psychologists (Janz & Becker, 1984) and is based on the belief that people do a cost-benefit analysis when considering changing behaviours. This analysis includes looking at the following points:

- The likelihood of the illness or injury happening to them
- The severity of the illness or injury
- The likely effect of behaviour change
- Whether or not making the change will have some personal benefit (Baum, 1998; Hijeck, 1984).

The participants in this study worked through the stages involved in the Health Belief Model in a less formal way as part of ‘reframing’ their lives after their heart attack. Cardiac rehabilitation based on this model would assist with the process of ‘reframing’ and assist individuals to regain ‘everydayness’. Programmes would also be able to focus more easily on the actual needs of individuals rather than on the perceived needs of all people who have suffered a heart attack.

A major drawback of this model is that for people like ‘Rosie’, who do not feel as if they have been ill, the motivation to change detrimental lifestyle behaviours such as smoking may not be present. Rosie did not feel that her heart attack was serious or severe and because of this she did not feel that she needed to rest and recover. Whichever model is chosen by health professionals as a basis for cardiac rehabilitation programmes, it is clear that the central focus needs to be finding out what kind of information and support each individual requires and planning ways to deliver this.

Recommendations for Practice

Most of the women in this study did not realise they were experiencing a heart attack despite publicity about signs and symptoms. There is a need to provide both women and health care professionals with more education relating to the signs and symptoms of heart disease in women so they are able to recognise the significance of such symptoms (O’Farrell, Murray, Huston, LeGrand, & Adamo, 2000). There also needs to be an educational focus on women as sufferers of CHD in the media rather than the current focus on men.

Available literature suggests that women do not attend cardiac rehabilitation as often as men (Everson et al., 1998; Hamilton, 1990; Parks et al., 2000; Thomas et al., 1996), and a smaller percentage of women are referred for cardiac rehabilitation (Ades et al., 1999). Health professionals need to ensure that all women who experience heart attacks are able to gain the support and information they need for recovery. Health professionals need information that will help them to identify the learning and support needs women have after a heart attack. They also must have the resources necessary to be able to set up rehabilitation programmes which meet these needs in ways that current phase two cardiac rehabilitation programmes do not.

In order to provide suitable cardiac rehabilitation programmes health professionals should have greater awareness of the individual needs of women who have experienced a heart attack. Although they have expert knowledge and skills, which can be applied to the rehabilitation of women who have experienced a heart attack, it is crucial that health professionals recognise that each woman is also an expert (Kamwendo, Hansson, & Hjerpe, 1998). To enhance our understanding of how women adjust to having a heart attack, further research is needed to identify women's experiences and factors that helped or hindered their recovery.

Women who wish to attend cardiac rehabilitation must be supported to do so. Those who do not wish to attend need to be offered other options to support their recovery. Research indicates women do not attend because of transport issues, having to care for dependents and feeling that they would have nothing in common with the rest of the group (Filip et al., 1999; McSweeney & Crane, 2001). Addressing these issues may improve women's attendance and participation. Health professionals will need to gain knowledge of each individual's home circumstances and put resources in place to provide assistance if women's attendance at phase two cardiac rehabilitation programmes is to be improved.

The desire of women to return to 'everydayness' must also be taken into account by health professionals. Assisting and supporting women to regain their everyday roles and responsibilities may make them feel more positive about their recovery from and their future after a heart attack. By taking into account the individual needs of participants and

their significant others, cardiac rehabilitation can be provided in an environment that is safe and comfortable for the client and in a way that meets their social and support needs.

Current nursing education focuses on teaching students about the classic symptoms of CHD. This focus needs to be changed to also include a wider range of symptoms and presentation. Current textbooks also focus on the more classic symptoms and presentation of heart attacks in men. Nursing education should provide students with knowledge of how to access, interpret and apply research to practice, so that more current research related to women can be used to improve patient outcomes.

Limitations

The first limitation of this study is its sample location and size. My sample was of largely middle class European females sourced through two different hospitals but within a reasonably close geographical location. Lack of time and resources to find a wider sample group also impacted on the number and range of participants. As a result of the selection process, theoretical sampling occurred through questioning rather than through the purposeful sampling of participants. However despite this I believe that the findings of this study provide valuable insight into how useful women perceive cardiac rehabilitation to be.

Some of the requirements for postgraduate study also provided limitations, for example the need to perform a literature review before commencing this research. This could have influenced my views about women and cardiac rehabilitation. To reduce this possibility a literature review that focused on women and heart disease in general was performed initially. This was then followed by a review that focused on women and cardiac rehabilitation. A further limitation is that of my background in cardiovascular nursing gave me preconceived ideas about the role and usefulness of both phase one and phase two cardiac rehabilitation programmes. This was dealt with by being aware that I had some preconceived ideas and actively trying to put those ideas aside. However I believe that rather than meeting my expectations of the role of cardiac rehabilitation in women's recovery, the study findings have shown that my ideas were not shared by the women who participated in this study.

Recommendations for Future Research

Although the results of this research are interesting they by no means answer all the questions I posed about women's perceptions of cardiac rehabilitation. Current research has tended to focus on what type of information men and women want (Ashton, 1997) rather than on the perceptions or experience of attending cardiac rehabilitation programmes. Recommendations for future research include:

- Research comparing men's and women's experience of the same programmes would be useful to help identify differences in perceptions of cardiac rehabilitation between men and women.
- Further research investigating the effect of co-morbidities on women's recovery from a heart attack is also indicated.
- Further research looking at how CR nurses make decisions about which clients/patients they encourage to attend cardiac rehabilitation and why people are treated in different ways is required as well as research looking at the consequences of this encouragement or lack of encouragement for patients.
- Research into the effect of roles and responsibilities on women's recovery from a heart attack would be of value.
- Research investigating factors which help or hinder women's recovery from a heart attack would be of value.
- No Maori or Pacific Island women agreed to participate in this research, future research of this type must specifically target these groups of women.

A large triangulated study, which compares men and women as well as a variety of different cardiac rehabilitation programmes around New Zealand, would be useful. Triangulation would combine the patient's experience and perceptions with quantitative data to give a broader picture of cardiac rehabilitation programmes.

Summary and Conclusion

'Regaining everydayness' through the process of reframing was the focus of recovery for the women in this study. Recovery involved moving along a continuum, which began with the onset of symptoms and moved towards them regaining the social roles they had previously fulfilled. This process involved coming to terms with the diagnosis of a heart attack and what this meant for their lives. Support for 'regaining everydayness' was

identified as an important part of the recovery process. Some of this support was provided by the cardiac rehabilitation nurses, but the influence of social factors affecting the recovery of each individual were not always taken into account.

It appears that although the stated aim is to facilitate patients “return to a full and active life by enabling the development of their own resources” (NZGG, 2002a, p. 3), the actual focus of some current cardiac rehabilitation programmes is on reduction of risk factors through lifestyle changes. Despite this misdirection, cardiac rehabilitation in its current form contributed in some way to participant’s recovery from a heart attack. However it failed to provide the type of support that these women identified as being important. Programmes need to be designed with the flexibility to meet the needs of different individuals or many women will miss out on the information and support they require. The Stages of Change Model and the Health Belief Model of community health education could provide starting point for planning future cardiac rehabilitation. Regardless of which model is used it is imperative that the specific education and recovery needs of each individual are taken into account.

Cardiac rehabilitation in its current form contributed to some extent to the recovery from a heart attack of these women, but did not meet all of their needs. Although this study is limited by the amount of time that was available to complete it and its focus on women only, I believe that the results give useful insight into the experience of a heart attack and recovery for the women interviewed. It is clear that much research into heart attack recovery for both women and men is still required.

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Appendix 1

Your Mobilisation Programme

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



21

(Silverstone, 2000)

Appendix 2

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

Women's Perceptions of the Contribution of Cardiac Rehabilitation to their Recovery from A Heart Attack.

My name is Wendy Day. As part of completing my Master of Arts degree in Nursing I am undertaking research related to women's experiences and perceptions of how cardiac rehabilitation has affected their recovery from a heart attack. I have a background in coronary care nursing and I am particularly interested in people's experience of illness and recovery.

I would like to invite you to consider participating in this research study. I would like to interview you whether or not you have attended hospital or community based cardiac rehabilitation. If you agree to participate I would like to interview you initially for about one hour. I would also like to interview you a second time to clarify and expand on what you have said.

If you are interested in being part in this research, please return the reply sheet that accompanies this letter in the postage paid envelope, or contact me on (06) 3258549. I will be available in the evenings if you have any questions. During the day please leave a message and I will return your call as soon as possible. Once you have contacted me I will send you an information sheet explaining the research and answer any questions you may have.

This study has been approved by the (...). Your participation in the research is totally voluntary and complete confidentiality will be maintained. If you have any questions regarding this research you can also contact my research supervisor, Lesley Batten; School of Health Sciences, Massey University, Palmerston North, phone: (06) 3505799 ext 2247.

Wendy Day
11 Kendalls Line
Rd 4, Palmerston North
Ph: Home (06) 3258549; Work (06) 9527001 ext 7436

Appendix 3

Reply Sheet

I am interested in taking part in the research study:

Women's perceptions of cardiac rehabilitation

Name:

Address:

Telephone Number:

Best times to contact me:

Information Sheet

Women's perceptions of the contribution of cardiac rehabilitation to their recovery from acute myocardial infarction.

Researcher: Wendy Day
Contact Details: Ph: (06)3258549

Supervisor: Lesley Batten, School of Health Science, Massey University
Contact Details: Ph: (06) 3505799 ext 2247

You are invited to take part in a study about how women perceive cardiac rehabilitation has contributed to their recovery from a heart attack (Myocardial Infarction). This research is being completed as part of a Master of Arts degree in Nursing.

In the past most of the research related to heart disease has involved males and excluded women. The results of these research studies have then been used to plan care and treatment for both men and women. With increasing numbers of women suffering from heart attacks and other forms of heart disease there is a greater need for research that deals specifically with women's needs in relation to care and treatment.

I am interested in finding out what women think about cardiac rehabilitation and why they do or do not attend cardiac rehabilitation programmes after they are discharged from hospital. Identifying how women experience cardiac rehabilitation will provide useful information to help cardiac rehabilitation programmes to further meet the needs of women.

I would like to talk with women who have had a recent heart attack. All women who have had a heart attack and been admitted to (city) or (city) Hospital's coronary care units or post coronary wards will be invited to take part. It is hoped that 10 to 15 women will be interviewed. If you consent to take part you will be interviewed in your home or another venue that you feel comfortable with. Participation in this study will involve an initial interview of approximately 1 hour and a follow-up interview of approximately 30 minutes to 1 hour.

If you agree, I would like to tape the interviews, which will then be typed up. The only people who will hear the tapes or see the transcriptions will be myself, my supervisor, and the transcriber. If you want to you may see the transcription or listen to the tape of your interview. You will be given the opportunity to edit the transcript if you wish.

Taking part in this study is completely voluntary (your choice). If you agree to take part you are free to withdraw at any time, without having to give a reason. This will not affect any future care or treatment that you may require.

You have the right any time during the research to:

Decline to participate.

- Ask questions about the research.
- Refuse to answer any particular question.
- Ask the researcher to leave at any time.
- Withdraw from the study at any time prior to the end of the second interview.
- Ask that the cassette recorder be turned off at any time.
- View any notes taken.
- Ask to view the transcription of your interview, discuss and amend it prior to data analysis.
- Provide information on the understanding that your name will not be used unless you give permission to the researcher.
- Be given access to a summary of the findings of the study when it is concluded.

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact the Health and Disabilities Consumer Advocate in (cities and phone numbers).

No material which could personally identify you will be used in any reports on this study. Your interviews will be allocated a number known only to myself, which will be kept locked away from material that may identify your name, such as your consent form. Computerised data will be stored on a home computer in a secure file.

It is intended that the results of this research will be presented in the form of a thesis, published in professional nursing journals and presented at relevant conferences.

If you have any further questions please feel free to contact me, or my research supervisor, Lesley Batten.

Thank you for taking the time to read this information.

Consent Form

Women's perceptions of the contribution of cardiac rehabilitation to their recovery from heart attack.

Researcher: Wendy Day

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

I understand that taking part in the 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 or future health care. I understand that no material which could identify me will be used in any reports on this study.

I have had time to consider whether or not to take part. I know who to contact if I have any questions about the study

I consent to being interviewed about my experience of cardiac rehabilitation and I consent to those interviews being audio-taped.

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

I _____ hereby consent to take part in this study.

(Full name)

Date:

Signature:

Appendix 6

Confidentiality Agreement

I understand the confidential nature of the material that I have agreed to transcribe for Wendy Day. I agree that I will discuss it only with her and I will not, at any time, share it directly or indirectly with anyone else.

I will ensure that the confidentiality of the material will be maintained and that at no time during the transcribing process will any other person have access to either the tapes or transcriptions except for Wendy Day and Lesley Batten (research supervisor).

I will ensure that all computer files related to this information are password protected and that, once transcribed, all copies (tapes, computer discs and hard copies) are returned to Wendy Day and the computer file deleted.

Full Name:

Signature:

Date:

Witnessed by:

Signature:

Date:

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