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WOMEN'S EXPERIENCE OF A MYOCARDIAL INFARCTION

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LUND UNIVERSITY
Faculty of Medicine

**SWEDEN
2011**

Doctoral Thesis
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To my father and mother

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ABSTRACT

Background: Coronary heart disease (CHD) is the leading cause of mortality in men and women in Western society. Few studies of CHD have been performed on women or with a focus on cardiac risk factors in women's lives. Results from studies of men have been generalized to women, which may be inappropriate or even dangerous.

Aim: The overall aim of this thesis was to describe women's experience of a myocardial infarction and to explore and describe important factors associated with this. Furthermore, to describe women's daily life five years later and the long-term follow-up resources in primary care.

Method: The first study (I) described women's (n=19) symptoms and reasons for delay in seeking medical care at the time of a first myocardial infarction. A content analysis method was used. The second study (II) looked at how women perceive stress in their daily lives at the time of (n=20) and after (n=14) the MI. The third study (III) examines how women cope with stress at the time of (n=20) and after (n=14) an MI. In study four (IV) the women (n=12) were interviewed five years after the MI. Studies II, III and IV used a phenomenographic method with contextual analysis. Study five (V) describes the results of a questionnaire sent to primary health care centres in Skåne, elucidating resources and cardiac rehabilitation possibilities.

Findings: The women had difficulties interpreting the symptoms or did not recognize the symptoms at all until they experienced their first MI (I). They had problems making the final decision to seek medical care. The women wanted support and help from a family member or a friend. Some women found it difficult to call for ambulance transportation and often first consulted the PHCC (I). Study II resulted in two description categories: the women conceived the stress as a personal trait and as a response to their immediate surroundings. The women had experienced being under enormous pressure at the time of the MI, which they found stressful. Furthermore, they had to assume a great deal of responsibility for their family and work. After the MI the stress continued to increase. Study III resulted in three description categories regarding the women's coping strategies with stress at the time of and after the MI: cognitive actions, social belonging and emotional diversion. The women became aware that they needed to make plans for their needs and it was essential for them to be confirmed. By talking to someone they trusted they received emotional support. Avoidance was used because they did not take their cardiac events seriously and tried just to resume their lives as if nothing had happened. Study IV showed that the women changed their lifestyle immediately and some needed time for reflection before they could make the prescribed lifestyle changes. The women found it difficult to continue with all the changes. Even five years after the MI they still needed support from health care professionals. A minority of the PHCCs (V) had nurses with special education in coronary heart disease and cardiac rehabilitation, and 5% of the PHCCs had nurses with a special position to take care of these patients. Of all centres 76% had access to a physiotherapist whereas there were significantly more

public PHCCs compared to private centres that had access to a physiotherapist. The same relation was found regarding access to a dietician.

Conclusions and implications: The women had difficulties interpreting the symptoms or did not recognize the symptoms at all until they experienced their first MI. For women it is important to recognize the role of stress as an essential risk factor for MI. The women described how they felt stress over a long period and how it affected them. They mentioned different strategies to cope with stress in their personal and professional lives related to MI. Even five years after the MI, that event had a significant impact on the women. An understanding of this phenomenon can assist primary healthcare, coronary care and rehabilitation nurses in supporting women, as well as their partners, to adapt their daily lives both before and after an MI. This thesis points out that patients suffering an MI need long-term support. Well-educated staff with adequate resources in primary health care can be of great importance.

Keywords: myocardial infarction, women, content analysis, phenomenographic method, stress, coping, rehabilitation, primary health care

ORIGINAL PAPERS

This thesis is based on the following papers, referred to in the text by their Roman numerals:

- I Sjöström-Strand A, Fridlund B. Women's descriptions of symptoms and delay reasons in seeking medical care at a time of the first myocardial infarction: a qualitative study. *International Journal of Nursing Studies* 2008;45:1003–1010.
- II Sjöström-Strand A, Fridlund B. Stress in women's daily before and after a myocardial infarction: a qualitative analysis. *Scandinavian Journal of Caring Sciences* 2007;21:10–17.
- III Sjöström-Strand A, Fridlund B. Women's descriptions of coping with stress at the time of and after a myocardial infarction. *Canadian Journal of Cardiovascular Nursing* 2006;16:5–12.
- IV Sjöström-Strand A, Ivarsson B, Sjöberg T. Women's experience of a myocardial infarction: Five years later. *Scandinavian Journal of Caring Sciences*. E-publication: 22 DEC 2010, DOI: 10.1111/j.1471-6712.2010.00849.x. In press.
- V Sjöström-Strand, A, Ivarsson, B, Sjöberg, T. Rehabilitation after myocardial infarction: Primary health care resources in a southern Swedish region. In manuscript.

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INTRODUCTION

In developed countries coronary heart disease (CHD), including myocardial infarction (MI), has been recognized as a major health problem [1;2] and constitutes the leading cause of premature death and morbidity. MI is not only a man's disease; it is also the single largest killer of women [3;4]. Below 55 years of age the risk of CHD in men is almost four times that of women [5]. Women's risk increases after menopause and, on average, women manifest the disease almost 10 years later than men [5]. Mortality from CHD has decreased in Sweden in recent years. The downward trend has been particularly strong for CHD in men, whereas the decline in women has been less impressive [6].

My interest in women's health and CHD came during the years I worked as a cardiac nurse and as a teacher in cardiology and cardiothoracic surgery. Then I met women who underwent percutaneous coronary intervention (PCI) or coronary arterial bypass grafting (CABG), and it was clear to me that an MI is not just a diagnosis and a special treatment, but in the middle of all technology there is a vulnerable patient. I realized that I wanted to learn more about women's experiences of an MI.

There is a difference between men and women in terms of treatment and, according to Wenger, less aggressive treatment may result in less favourable outcomes for women [7]. To be afflicted with MI is a very traumatic experience physically and psychosocially. The person has experienced an abrupt change from being well to being seriously ill and has been reminded of her/his own mortality. Acute myocardial infarction leads to rapid changes in the life situation, a constant struggle with a life-threatening illness and an insecure future. Such an experience seems to produce an overwhelming loss of confidence and causes anxiety and depression [8]. Surviving an MI is a major life event for both the patient and the next of kin [9].

Women experience higher rates of mortality after MI and poorer outcomes [10]. Poor clinical outcomes in women after an MI in conjunction with increased age may require multiple medications to manage symptoms [11]. Ayanian reported that women with MI had increased risk of reinfarction and death as a result of advanced age and severity of the coronary heart disease [12]. Women have reported lower levels of physical functioning and activity, and significantly higher levels of anxiety and depression [13]. One year after an MI, women reported lower health-related quality of life concerning physical and social functioning, bodily pain, vitality, and mental health [14]. Therefore, it is important to pay more attention to female recovery than has been done so far. Although most women do survive an MI, little is known about their recovery. It has been shown that women who have cardiac events at a younger age have a worse prognosis than men [10].

Health promotion through rehabilitation and secondary prevention improves women's general health and well-being after an MI [15]. Most risk factors causing CHD are modifiable by changing an individual's health habits [16]. However, it is very difficult to initiate and sustain lifestyle changes after a cardiac event. To

diminish female, as well as male, illness and mortality after an MI, risk identification and long-term lifestyle change programmes are important [15]. Primary health care centres (PHCC) should have strategies and resources to supply CHD patients with the necessary facilities.

Socio-economic status and CHD

It is well documented that those with low income have increased mortality from CHD [17]. Furthermore, Barbareschi et al. reported that patients with high socio-economic status have a better outcome at the pre-morbid assessment, with fewer depressive feelings and better physical function, and similar results were repeated 6 and 12 months after the diagnosis [18]. Understanding the psychosocial factors at work for patients with MI is important and has become more evident during the last few decades. Such factors have been shown to be important for the increased risk of MI in both men and women [19;20]. Lower socio-economic status has been associated with poorer diet in people with CHD in terms of overall diet [21]. Clark et al. recently studied different factors for promoting the capacity to consume a healthy diet in CHD patients with low socio-economic status [22]. Food consumption was not principally related to knowledge but was constrained by an ever-present scarcity of resources and the need to prioritize other daily living expenses perceived as being more important than diet. There are many possible pathways to the development of CHD, all of which involve the interplay between the individual body and various social and economic forces [23]. Shaw et al. suggest that, among a variety of socio-economic factors, income is the strongest estimator of cardiovascular morbidity and mortality [24].

Prehospital and hospital delay

Prehospital delay has been found to be an important predictor of patient morbidity and mortality. Women's perceptions of their low risk of CHD can influence the decision-making process. These misconceptions may lead women to underestimate their risk of CHD and they may thus fail to seek early interventions to prevent unnecessary morbidity and mortality [25;26]. As a result of these assumptions, women are less likely to be referred for diagnostic tests, to receive treatment, such as cardiac surgery, and to be more likely to be referred at a later stage in their illness [27]. Moreover, it has been shown that women perceive breast cancer as a greater risk than CHD, which may lead women to underestimate their risk of CHD [25].

Research during the last decade has provided some insight into the experiences of women with CHD. It seems to be some variability in the symptoms, especially among women [4]. Rosenfeld et al. reported that the severity of symptoms and slow progression or intermittent symptoms were clinical factors most predictive of delay in seeking care among women [28]. Generally the women proceeded to hospital when self-treatments and their network were unable to manage the situation [29].

Delay can lead to lethal complications or sudden death. Age has been suggested as a possibility for the difference between men and women. Women in the age group 65–75 years have the highest percentage of atypical symptoms. Atypical symptoms include epigastric or abdominal pain, nausea, vomiting, diarrhoea and feeling unwell [30]. Patel et al. made a review of the literature and their results showed that in several of the studies women had significantly more atypical symptoms such as jaw and back pain, whereas men reported more chest pain and diaphoresis [31]. Isaksson et al. pointed out that there are no major gender differences in prehospital delay or type of symptoms. However, over time the portion with typical symptoms decreased in men and increased in women [32]. There is still a need to discover how early warning symptoms differ for women. Such information could then be used to design screening approaches that will facilitate women's entry into the health care setting.

Treatment of acute myocardial infarction

After an acute cardiac event, such as MI, patients are treated with the following strategies: medical therapy and surgical revascularization by means of percutaneous coronary intervention (PCI) or coronary by-pass surgery (CABG) [33]. Usually the patients are hospitalized for less than one week after such treatments.

The choice of treatment method has undergone a rapid change during the last decade. Medical therapy is still a mainstay regarding essential risk-factor modification and antithrombotic therapy. Bypass surgery of the coronary arteries has changed and become less intensive in certain cases with the introduction of minimally invasive beating-heart surgery. The field that has changed most is PCI, with the introduction of intravascular stents and drug-eluting stents. The first PCI was performed on a human being in 1978 [34]. Twenty-five years later, almost 734,000 PCIs have been conducted in Europe alone [35]. During the last few years PCI has overtaken bypass surgery as the dominant revascularization treatment for CHD [33;36]

Hwang and co-workers found that patients were surprised at having a relatively non-invasive procedure (PCI treatment) and shorter discharge times [37]. Despite having less contact with health professionals due to the short hospital stay, the patients seemed to have understood the nature of their condition and said that they were making significant changes to their life in terms of secondary prevention. Furthermore, it has been reported that patients undergoing revascularization treatments share the perception that the treatment is curative [38]. However, it has also been shown that MI patients did not understand the chronic nature of their illness [39]. Patients inevitably have different understandings of their illness and treatment.

Cardiac rehabilitation and secondary prevention programmes

The initial period following hospital discharge is often characterized by fear and uncertainty. There is evidence that women are more likely to develop cardiac distress symptoms and complications after an MI than men [40]. In addition, rehabilitation activities will change over time, beginning in the ambulance and the hospital and continuing after the woman leaves the hospital. Rehabilitation continues for 3–6 months following the hospital stay, until the patient is more physically independent and can begin making long-term lifestyle changes [41]. Research also finds gender differences both in cardiac rehabilitation preferences and in the use of such services. More men than women receive referrals to cardiac rehabilitation programmes [42]. Women report more difficulties with accessibility in terms of both transportation and financial affordability, and attribute fewer benefits to participation [43]. One possible explanation for this finding is that cardiac events generally occur later in women than in men and tend to have more severe pathology with poorer prognosis [44].

Cardiac rehabilitation programmes have become a meeting point for multidisciplinary teams to promote a range of health care behavioural changes, including medication adherence that have been shown to reduce further cardiovascular risks and increase the quality of life [45]. The importance of secondary prevention programmes in reducing risk factors and in improving functional status and quality of life has also been increasingly recognized [46]. Studies have shown that intervention with an intensive focus on modification of risk-factor-related lifestyle behaviours for CHD patients can reverse the underlying coronary artery disease [47;48]. Almerud et al. pointed out in a recent study that non-attendees in cardiac rehabilitation programmes had poor knowledge about biological causes and hereditary factors [49]. CHD rehabilitation includes a broad spectrum of different solutions, from nurse-led individual interventions to peer-led group support [50].

Studies on cardiac rehabilitation and health educational programmes have shown that future recurrences might be reduced as a consequence of a slower progression of coronary atherosclerosis or stabilization of already existing coronary plaque [51]. There is strong evidence to support the efficacy of secondary prevention programmes for CHD patients regarding morbidity and mortality [15]. Hallman et al. pointed out that the intervention group had significantly larger overall lifestyle changes than the control group after 12, 24, 36, and 60 months [40]. Another way to increase compliance with the rehabilitation programme is to include cognitive and behavioural components [52]. One programme that adopted a problem-based learning approach for rehabilitating patients with CHD found that 90% of the participants reported active lifestyle changes [53].

Rehabilitation programmes that include both group and individually oriented components for both intensive and diversified psychosocial support have been shown to be effective in producing good outcomes [54]. Learning needs for patients with MI will vary depending on the stage of recovery; for example first-time CHD survivors may have specific learning needs. In addition, nurses and patients may have different

views on their learning priorities. It is important to be aware of the learning needs of patients and families [55]. Orth-Gomer et al. found that a group-based psychosocial programme, designed to reduce stress after an MI, resulted in a significant decrease in mortality when compared to usual care [56]. Hagberth et al. found that women experience advantages and benefits by meeting others in the same situation [57]. Rehabilitation programmes should include information about the diet, exercise, general health education, social support and stress management. Support in the form of information and easy access to the health care system are of great importance for CHD patients, as this provides a feeling of security during the recovery period after an MI [58]. Such considerations remain important for the rest of the patient's life, with information on managing symptoms and lifestyle factors most important for both the patients and spouses/partners [59;60].

Gender must be seen as an important factor in health care planning and delivery, and CHD is a prime example of a disease in which there are known gender differences [61]. An advantage for women is that CHD is manifested 10 to 20 years later in women than in men, but women with MI have more physical, psychosocial and medical disadvantages than men [62]. The promotion of healthy lifestyles has been one important way of achieving long-term health gains. Since women with CHD perceive stress as a primary cause of MI, it should be reduced or prevented, yet there are many barriers to prevention [63;64]. Many patients show insufficient insight into CHD to really understand their health care professionals' explanations [65]. Decisions about health-related behaviour are complex, and are made in the context of an individual's background and life circumstances [66]. It is well known that women do not necessarily implement or maintain changes they are advised to make in lifestyle [67]. Some patients may not fully understand or accept the relationship between knowing about CHD and changing their behaviour to reduce their risk [68].

Following a diagnosis of CHD, many patients resist effective rehabilitation and lifestyle changes, reverting to their former social and work habits. One explanation for patients' low level of motivation for long-term life changes may be that they see their MI as an acute event rather than as a chronic medical condition [69]. They have to adapt to a sick heart, learn to interpret the signals from the heart and also be able to "listen" to it [58]. These difficulties not only increase after hospitalization but often remain over at least the first year after the MI [70;71]. After an MI patients often experience an initial period of internal disorder, fear and uncertainty. They may show signs of fear of the future, of death, and of a recurrence of their acute episode [72]. Psychological difficulties related to MI are commonly linked to stress and its management [73]. Psychological distress adversely affects the patients' quality of life as well as their prognosis irrespective of disease severity [74].

The concept of stress

The term stress is usually used with notorious vagueness in both experimental and clinical studies [75]. The Oxford Dictionary defines stress as: pressure, tension, physical or mental strain. Historically, the human stress response has been characterized metaphorically as fight-or-flight in the face of threat. Seyle described stress as the “non-specific response of the body to any demands” [76]. Stress is generally seen as the factor or set of conditions that are being coped with [77]. During the 1970s, Lazarus described stress reactions as dependent on how a person consciously interprets or evaluates the importance of harmful, threatening or challenging events [78]. The works by Lazarus and Folkman broadened the view of stress from one simple mechanical response to a threat, to a view that included a person’s interpretation of that threat. The key elements of the stress process are the individual’s perception of the ability to cope with the situation [77]. Stress has been defined as an imbalance between the demands on a person and the inner and outer resources that person has available to meet such demands [77]. Different types of stress reflect individual differences in sensitivity and vulnerabilities [79]. Stress is categorized as neither good nor bad, but as reflecting the degree, type and situation in which it arises [77].

Negative emotional stress has also been found to trigger episodes of silent myocardial ischemia. Symptoms such as fatigue, depression and burnout affect more and more people, especially among those who frequently seek medical treatment due to various symptoms [80]. It is becoming increasingly evident that symptoms that appear to be subjective or psychosomatic should be perceived as signals of ongoing stress [81]. Illness can be a source of stress because of the various demands on the individual [82]. When the demand is perceived as threatening, unpleasant or overwhelming, it becomes a stressor that requires mobilization of resources to adapt and cope with it [82]. Byrne and Rosenman linked emotional stress, personality types, sociocultural and psychosocial factors with the development of CHD [83]. They divided patients into two behavioural classes or patterns. On the one hand, participants were identified as type A, that is, ambitious and having an accelerated rhythm of life. On the other hand, participants characterized as type B were calmer and more relaxed. The authors concluded that the incidence of CHD was lower in type B participants [83]. However, it has also been reported that there is no clinical evidence that type A behaviour has an effect on CHD [84].

Stress-related illnesses are increasing in our society [85]. The concept of stress encompasses several factors from external stressors such as job stress, life events and financial problems. Potential reactions to stress are depression, exhaustion, anxiety and sleeping difficulties [86]. In Sweden, sick-leave rates for stress-related ill health have risen dramatically [87;88]. Research shows that stress and burnout contribute significantly to physical and mental illness [89]. Gassner et al. found that patients with MI described stress as the cause of their illness. Paying attention to unhealthy and stressful environments in people’s daily life and actions taken to prevent stress can benefit not just individuals but also the rest of the family [29]. It is therefore

important to continue studying the relationship between stress and ill health within the nursing profession [90]. Paquet et al. found that patients seemed satisfied with the care they received for their physical problem; however, stress remained a major concern [50]. Also studies with a qualitative design are especially required in order to gain a deeper understanding of the women's thoughts and feelings. Knowledge of patients' conceptions of coping with stress at the time of and after an MI is helpful of sustaining their recovery [91].

Work stress

Work organizations, entailing increased competition and workload and less job security, have increased the importance of the work environment as a source of potential harmful stress reactions [92]. It has been estimated that 10 to 40% of the workforce suffer from work stress, and at least one third of these have severe chronic-psychosocial stress [85]. One of the leading theoretical models of work stress is the job strain model (demand-control model) which was introduced by Karasek in 1979 [93]. Its basic idea can be summarized as: two relevant dimensions of the structure of tasks interact to produce strain reactions: high demands on the job and low control over one's tasks [93]. Work stress tends to be found more often in individuals of lower socio-economic status; it is also associated with poorer social support, greater conventional cardiovascular risk factors, lower education levels, and certain psychological traits [94]. Lazlo et al. recently found that job strain is associated with poor long-term prognosis after a first MI [95]. Work stress may have a more deleterious effect in terms of CHD in men than in women. There is a long-standing connection between women's ill health and high demands with little room for decision making [96]. The highest job strain occurs in workers with high psychological work demands but little job control. In the domain of the demand-control model, men seem to suffer more from the problems around control issues [97], while for women demands and social support appear to be of greater importance [19]. Work-related life events characterized by high demands, competition, or conflict have the potential to trigger the onset of MI [98]. Furthermore, women seem to be more sensitive than men concerning psychosocial risk factors for CHD, including workload, physical and emotional stress reactions and burnout [40]. Contrary results from a study by Blom et al. showed that working after an MI event was associated with a better psychosocial profile among women under the age of 65 [99]. However, it is important to recognize that working life is under continuous change, and this process causes variation in the relative importance of existing stressors and the possibility of new stressors emerging [100].

Marital and family stress

The employment rates of Swedish women in the last few decades have been largely equal to those of Swedish men. However, even if men and women today share many responsibilities, women still spend more time than men carrying out household tasks [101]. Women's main sources of daily stress are found in the family sphere, rather than at work. Severe and chronic marital problems are significantly associated both with depression and with poorer prognosis in women with CHD, but stress at work is not [102]. Studies of psychosocial adjustment after a first MI have compared women

with men and indicate that women report more mood disturbances, anxiety, depression, psychosomatic symptoms and sleep disturbance [19;62]. Thus it is important to explore how women perceive their life situation at the time of and after an MI, and especially how they perceive events in their daily living. Moreover it should be beneficial to obtain the women's overall perspective and to make them aware of their private and professional lifestyle.

Women often seem to have problems giving enough priority to their own health because they often care more about their children and the whole family situation than about themselves [103;104]. In contrast, men describe stress as being more related to their work. One study showed that women engaged in demands of both family and work may have higher levels of daily stress, potentially leading to a worse health outcome [105]. The serious threats to women's cardiovascular health come from multiple stressors, multiple roles and influences [106].

The Stockholm Female Coronary Heart Risk Study showed that chronic problems and difficulties in a relationship with a spouse or cohabitant increased the risk of a recurrent cardiac event three-fold during a 5-year period, whereas work stress did not worsen the prognosis [107]. Blom et al. found that a high degree of perceived stress within the marriage is associated with poorer social relations among middle-aged women with CHD [108]. Another form of domestic stress that has been associated with increased risk of CHD is caring for a disabled or ill spouse. The stress from seeing loved ones suffer, added to the stress from financial burdens and pressures of balancing work with care giving, may contribute to risk of CHD [109].

The concept of coping

The term coping is very widely used in nursing. The ability of people to cope with a given set of circumstances, whether as patients or next of kin, will play an important role in the effectiveness of nursing interventions. Helping people to cope, and to believe in their ability to do so, is an integral component of nursing care [110].

Lazarus started to pay attention to people's ability to cope with common life conditions [78]. The individual adaptation process is described best by means of stress-coping models, of which Lazarus and Folkman's model is the best known and most widely used. Lazarus focused on psychological rather than physiological stress and looked upon coping as a transactional process. The functions of coping include managing or altering the problem causing the distress and regulating the emotional response to the problem. Furthermore, Lazarus explained that the individual first appraises the stressor in two ways [111]. In primary appraisal, the person assesses to what extent stress is involved. Personality characteristics come into play at that stage. Secondary appraisal then occurs, to judge what the person can do to deal with the situation, prevent harm, and improve things. Secondary appraisal involves considering the options, constraints and resources available, including social support. The resulting coping behaviour to manage the demands of the stressful event or

process has two functions: dealing with the problem (problem-focused coping) and regulating coping (emotion-focused coping). Research has shown that people tend to use a mixture of types of coping in any situation. Thus an attempt to cope with the stressors is made by various ways of coping, namely information-seeking direct action, inhibition of action and intrapsychic modes [112].

Coping serves as a moderator between stress and adaptational outcomes [113]. Coping with an MI can be conceptualized as managing stress (emotion-focused), completing instrumental tasks (problem-focused), and attending to each other's needs (relationship-focused) [111].

Finnegan et al. found that an overwhelming majority of men and women reported that they never had planned what to do in the event of an MI, nor had they discussed symptoms or acting with their physicians [114]. The period immediately after discharge from the hospital after an acute MI is a stressful and vulnerable time about which little is known [91;115]. Therefore, when studying how patients cope with illness it is necessary to identify particular threats of immediate concern to the patient and to treat them separately, rather than broadening the focus of attention to the overall illness. It is then important to study coping strategies related to each one of the threats to describe what patients think and do in their attempt to cope [78]. Patients diagnosed with MI employ various strategies to regain control and reduce stress [116]. Women often minimize the impact of the disease. They tend to use coping strategies such as denying and avoiding the MI symptoms and trying to remember information about disease [117-119].

Coping and social support

It has been shown that social support as a coping resource has an indirect and direct effect on health, health behaviour and the use of health services [120]. Social support is defined as the interactive process in which emotional concern, instrumental aid, information, and appraisal are obtained from one's social network [121]. A social network is defined as the web of identified social relationships that surround an individual [27]. There is evidence that social support influences participation in health behaviours conducive to reduced cardiac risk, but support also has a direct effect on recovery from an MI [122]. Social support moderates the effects of job strain, anger and depression on CHD incidence, and lack of social support at work is particularly associated with raised risk of CHD [123]. Social support function is a buffer and a source of energy to struggle, and together with external support it helps to rebuild health [58]. Support groups may provide a valuable way for patients and family members to learn about problems and experiences similar to their own and to see how other families have managed to handle the situation [71;124;125]. Further developing an integrated lay and professional support network, rather than focusing on the disease, seems to require a concerted effort to provide a more appropriate and positive health/illness perspective for the patients and families [126].

Few studies have focused on how women perceive their daily life in terms of stress before and after an MI. Furthermore, most studies have so far assessed short-term outcome after MI. Health care professionals with special knowledge of CHD interact on various levels with women up to one year after the MI. Subsequently there is a lack of knowledge regarding long-term follow-up, and very little is known about the resources and strategies for CHD patients at the PHCCs.

AIMS

The overall aim of this thesis was to describe women's experience of a myocardial infarction and to explore and describe important factors associated with this. A further aim was to describe women's daily life five years later and the long-term follow-up resources in primary care. The specific aims of the included papers were to explore and describe:

- women's symptoms and reasons for delay in seeking medical care at the time of a first myocardial infarction (I).
- women's perceptions of stress before and after an MI (II).
- how women cope with stress at the time of and after an MI (III).
- how women conceived their health and daily life five years after an MI (IV).
- primary health care centres' resources and strategies for CHD patients in a southern Swedish region (V).

MATERIAL AND METHODS

Material selection

Participants in studies I–IV

Twenty women were selected during 2002–2003 from a Coronary Care Unit (CCU) at a University Hospital in southern Sweden. In accordance with the phenomenographic tradition [127] and to ensure a broad sample with maximum variation, a strategic selection was carried out with respect to age, civil status, number of children and education [128] (Table 1). The women were interviewed on the second or third day of hospitalization after an MI (I–III). In study I nineteen women were interviewed and in study II and III, 20 women were interviewed and fourteen of these 20 women took part in the second interview, which was performed 4–10 months after the MI. Study IV includes 12 of the originally participating women, who were interviewed 5 years after the MI. (Table 1)

Table 1. Demographic characteristics of the women participating in studies II, III and IV.

	At time of the MI (n=20)	After the MI (n=14)	Five years after the MI (n=12)
Age			
30–40	3	3	-
41–50	2	1	2
51–60	3	2	2
61–70	7	4	4
71–80	5	4	3
81–90	-	-	1
Education			
Primary education	9	6	7
Upper secondary education	5	3	2
University education	6	5	3
Marital status			
Married/living together	12	8	7
Single	8	6	5
Children			
0 children	2	1	-
1–2 children	11	7	8
children	5	5	3
>3 children	2	1	1
Follow-up interviews			
After 4 months		5	
After 6 months		6	
After 10 months		3	

Participants in study V

The responsible managers at all 137 public and private PHCCs in Region Skåne were invited to participate as informants. Answers from 91 (66%) of the PHCCs were finally included in the study.

Design and method approach

Study I

An exploratory design based on qualitative content analysis to describe women's symptoms and their decision to delay seeking medical care. The content analysis method is especially suitable for analysing situations or documented processes [129]. Content analysis initially dealt with the objective, systematic and quantitative description of the manifest content of a text, but over time, the method has expanded to include also interpretation of latent content [130]. Both manifest and latent content analysis methods deal with interpretation, but the interpretation varies in depth and level of abstraction. Manifest content analysis is about the surface and visible components in the text, i.e. what the text says, and latent analysis is concerned with the underlying meaning, i.e. what the text talks about [130]. Using both latent and manifest content analyses provide more insightful and meaningful findings than using either approach alone.

Studies II, III and IV

An explorative and descriptive design inspired by phenomenography was chosen. Phenomenography is the empirical study of the differing ways in which people experience, perceive, apprehend, understand and conceptualize various phenomena in and aspects of the surrounding world. This approach was developed at Göteborg University, Sweden, and originated in the early 1970s as a learning method. Closely related to the phenomenographic tradition is contextual analysis, a methodology characterized by an open, explorative and comprehensive approach [131]. The aim of contextual analysis is to elucidate the parts and their internal relationships of phenomenon which are conceived as a whole in its context. The contextual analysis is analytic in the sense that the main focus is on differentiating parts of the data [132]. Phenomenography has similarities to phenomenology since both approaches aim to describe phenomena, but from different viewpoints. Whereas phenomenology aims to describe the essence and commonality of phenomena, the aim of phenomenography is to explore and describe the different ways in which people experience, see and conceptualize phenomena in the lived world around them.

Phenomenography makes a distinction between what something is and how something is perceived. In the first case, interest is directed towards the phenomenon as such, which is called the first-order perspective. How the person perceives it in reality is known as the second-order perspective [131]. It is the second-order perspective that is unique to phenomenography. Interviews can form the empirical foundation for examining conceptions. The conceptions are based on each individual's conceptions of the phenomenon. This includes contextual consciousness,

where context is the area in which conceptions of the phenomenon appear and are brought together into different categories that are not identified in advance [131].

The findings in phenomenographic studies have often been found useful in health care for trying to understand the nature of individual experiences of health issues [133]. The application of a phenomenographic approach to a nursing research study is to examine and emphasize the differences between how different patients experience their emotional states and needs [133].

Study V

A descriptive study was conducted to investigate the strategies, resources and rehabilitation and secondary prevention programmes of the PHCC and to compare these aspects of public and private, rural and urban PHCCs. The production of a questionnaire was inspired by other studies [134;135]. It contained 26 closed dichotomous or multiple choice questions. The questions were tested for face and content validity by an expert panel of one specialist in general medicine and one general practitioner and three nurses experienced in the topic. None of the experts were working in the region under investigation.

Data collection

Study I

An interview guide was constructed based on a literature review and personal experience as a cardiac nurse. Prior to implementation one pilot interview was carried out in order to evaluate the interview guide, resulting in slight changes with regard to follow-up questions. The focus of the questions was to prompt the women to describe their symptoms and reasons for delay in seeking medical care. The initial questions were: Can you describe the symptoms related to the MI? How did you interpret the symptoms? How did you act with regard to the symptoms and seeking medical care? The progression of the interview varied according to the follow-up questions needed to further explain the answers to the initial question. Such questions were: Can you describe that in more detail? What do you think about that? During the interviews, the participants were encouraged to express themselves in their own words. The tape-recorded interviews took about one hour and were transcribed by the main author.

Studies II and III

A stress- and coping-related interview guide was constructed based on a literature review and the author's experiences as a cardiac nurse. The interviews were performed during October 2002 and November 2003. One pilot interview was carried out in order to evaluate the interview guide, resulting in slight changes with regard to follow-up questions. The women were asked questions in order to elucidate their experiences concerning stress and coping with stress before and after an MI in their daily life. The initial questions in study II were: What does stress mean to you? How

do you describe stress? Did you experience stress before/after your MI? Can you describe the stress and how you experienced it before/after your MI? The initial questions in study III were: What does coping with stress mean to you? How would you describe coping with stress? How did you cope with stress before/after the MI? The progression of the interview varied in accordance with the follow-up questions that were needed to explore the initial question. These were questions like: Can you describe that a little further? What do you think about that? During the interview the women were encouraged to express themselves in their own words when answering the questions.

Study IV

A thematic or semi-structured interview technique, which is the most common data collection method in phenomenography [136], was used. The interview guide consists only of opening questions, such as: How has your situation been since we met five years ago? The subsequent dialogue may vary considerably between informants [128]. The interviews, which took about one hour, were tape-recorded and transcribed by the main author.

Study V

The questionnaire was sent to the responsible managers of all (public and private) 137 PHCCs in Region Skåne. Information regarding the research and a pre-paid envelope for return of the questionnaires were attached. Following two reminders within two months, a total of 91 (66%) of PHCCs completed and returned the questionnaire.

Data analysis

Study I

The interviews were performed to investigate the women's understanding of the symptoms of their MI and reasons for delay in seeking medical care. The manifest and latent content analysis was performed by the two authors in parallel [130]. Familiarization with the recorded material was accomplished by repeatedly reading the transcripts. The text about the participants' understanding of symptoms and delay in seeking medical care was divided into major units that were further condensed into conceptual units and labelled with a code. The differences and similarities among various codes were compared in order to sort them into subcategories and categories. Through a process of reflection and discussion, the authors agreed on the categorization [137].

Studies II, III and VI

The data were analysed using the phenomenographic procedure, which comprises seven steps according to Dahlgren and Fallsberg [136].

1. Familiarizing. The analysis started with a reading of the whole text in as open-minded a way as possible in order to gain an overall understanding of the phenomenon.
2. Condensation. The main author reread the text of the participants' interviews several times in order to identify each women's most significant statements about how they perceived and coped with stress and also how they conceived their daily life five years after an MI. The answers were selected to describe what the participants contributed to the discussion. This step included some reduction of the transcribed interviews.
3. Comparison. Next, to identify sources of variation or agreement, we compared ways in which the interviewees experienced the phenomenon of MI.
4. Grouping. In this step the statements that seemed similar were grouped into appropriate patterns within the overall picture of the perceptions.
5. Articulating. The structure of the similarities within each group of statements was described as a preliminary category. Steps 4 and 5 were repeated several times until the analysis was considered satisfactory. The focus of attention was shifted from the relationships within the perceptions to the relationships among the categories.
6. Labelling. Each category was given a suitable name or label to delineate according to the structure of what was articulated.
7. Contrasting. This step involved comparing similar or different levels of understanding expressed by the interviewees. A process called negotiating consensus was followed in which categorization and interpretation were discussed with experts in the field – two cardiac nurses – to reach agreement about the final status [137]. The categories were hierarchically ordered and labelled as A and B, in accordance with the best understanding. Such a hierarchically ordered set of categories is known as outcome space. The outcome space thus depicted the different ways in which interviewees understand the MI phenomenon. This line of reasoning applied, not only to the understanding of the text as a whole, but also to the various topics treated therein [138].

Study V

Descriptive statistics were used. The PHCCs were divided into main groups according to whether they were public or private, and whether they were situated in an urban or rural area. These main groups were also sub-grouped as public-urban or public-rural and private-urban or private-rural. Fischer's exact test was used to assess dichotomous questionnaire data, while ordinal data were tested by Mann-Whitney's non-parametric method.

ETHICAL CONSIDERATIONS

Studies of this doctoral thesis have taken into consideration the ethical principals relevant to human research and in line with the ethical principles of the Declaration of Helsinki [139]. The principle of respect for autonomy entails, among other things, the person's right to make choices and to take actions based on his/her personal values and beliefs [140]. Consequently, we informed potential participants of the purpose of the study and reassured them that any information they provided would be kept confidential and that the results would be presented in such a way as to protect their privacy and identities. To respect their autonomy the participants were asked if they were willing to take part in the study and informed that the interviews would be tape-recorded (I–VI). Verbal and written consent was collected from each participant. Participation was voluntary, and the participants were told that they could withdraw at any time according to the principle of autonomy (I–V). In addition, they were assured that if they chose to not participate in the study or interrupted their participation, or withdrew from it, this would not adversely affect their care or treatment. During the interview the women were encouraged to express themselves in their own words; they were supported to narrate their thoughts in relation to the semi-structured interview guide. Furthermore, the participants were told that the result would be presented in such a way that no one could be identified. Contact information was given in the questionnaire and the respondents were asked to call or write if any questions or thoughts arose (V). Permission for the studies was obtained from the Ethics Committee of Lund University, Sweden.

FINDINGS

Study I

Women's experience of symptoms

The women had difficulties interpreting the symptoms or did not recognize the symptoms at all until they had experienced their first MI. They had difficulties viewing themselves as being at risk of CHD. The women thought that they were too young or old to have an MI. Furthermore, the women's own thoughts and concerns about their lifestyle made it difficult to interpret the symptoms as something serious, i.e. they believed that they had a healthy life. Evaluating symptoms in a period of time before the MI, the women described that the symptoms increased in severity and occurred over a period of weeks or a month before they acted on them. The women had prodromal symptoms with fatigue or discomfort in the chest before the MI. The women's main description of symptoms at the time of a first myocardial infarction involved pain in many different ways. They described the pain as coming rather acutely and suddenly or that the symptoms did not appear typical of MI or excessively painful. They experienced the pain as having pressure over the chest. Although the pain was difficult to manage, they wanted to wait at home, thinking that it would disappear.

The women also had prodromal and atypical symptoms and they often tried to find explanations for this. They did not suspect MI, although they had a family history of CHD. They were aware that they had several family members, such as their parents, siblings and other relatives, who had died of CHD, but they never considered themselves in the risk zone for having an MI. The women described how the chest-related symptoms caused anxiety. Anxiety and discomfort emerged when they did not recognize the pain and they described it as something strange.

Delay in taking action

The women tried "self-care coping", doing other things to handle the pain and discomfort rather than asking for professional help. They used different kinds of strategies for curing themselves, such as taking medication or resting for a while. It was very difficult for them to understand how serious the symptoms were. The women tried to persuade themselves that the symptoms would disappear. They convinced themselves that it was something else. They tried to link and explain the possible causes of their symptoms with reference to increasing age, stress, pain or tiredness due to hard work. The symptoms were initially ignored, followed by taking medication, changing position or sleeping. The women had problems making the final decision to seek medical care. They wanted to have support and help from a family member or a friend. Some women found it difficult to call for ambulance transportation and often consulted the PHCC first.

Study II

How women experienced stress in connection with the MI

The descriptive categories and conceptions are given in Table 2. The women described the stress as restlessness and worry emanating from within. They tried to have everything well organized and in control. They were afraid of not having control over their lives both in the family and in working life. Having such high demands was exhausting. This was extremely stressful and described as never being able to sit and rest. The women stated that a stressful life had caused their MI. Prolonged anxiety was very difficult to live with in everyday life; for example, the anxiety had arisen because of a long conflict with a family member and was described as long-term stress. They also expressed that they experienced their lives were no longer meaningful. Daily life was meaningless due to the death of a partner, or they lacked the strength to go outdoors. Their life had become more depressing since they retired, their loneliness created stress and fear. There were also conditions that triggered ill health. These women suffered from a multitude of diseases and conditions such as diabetes, rheumatoid arthritis and severe headache.

Table 2. Distribution of descriptive categories and perceptions of the women interviewed at the time of and after a myocardial infarction (MI).

Descriptive categories	Perceptions	At the time of the MI	After the MI
Personal traits	Restlessness	X	X
	Prolonged anxiety	X	X
	Having a meaningless life	X	X
	Conditions that trigger ill health	X	X
	Being preoccupied with thoughts	–	X
Effects of the immediate surroundings	Being depressed and lonely	X	X
	Long-term frustration	X	X
	Being stretched to the limit	X	X
	Demanding responsibilities	X	X
	Financial burden	X	X

Depression, frustration, and loneliness apparently played a large role in the women's interpretation of what caused their MI. The women described various kinds of stress in relation to their immediate surroundings, such as caring for a sick relative alone, without support. They also described that their friends had abandoned them when they really needed support. The lack of support from the community and friends was expressed as reasons for their MI. Furthermore, the women described the stress as being depressed and lonely. Over the long term such feelings made both family and working life seem stressful, leading to chronic periods of difficulty sleeping and lack of strength and extreme tiredness for which they found no suitable explanation.

Overwhelming financial or family responsibilities also contributed to the participants' ultimate illness. They also described how they were stretched to the limit between their private and professional lives and how they had difficulty keeping up with everything. The women in the present study also had heavy responsibilities for people around them. Furthermore they were largely responsible for the family finances or struggled to raise children alone. They had problems setting limits in daily life when people around them asked for help. The women were so stressed that they could not allow themselves to be ill. Yet ironically, when taken together, all these factors triggered their MI.

The women in the present study experienced MI as a traumatic event. They described how they conceived stress at the time of the MI and how the stress grew in the hospital and after being discharged from the hospital. Coming home from the CCU was stressful because they did not have the strength to carry out their daily responsibilities as before. This created a great deal of restlessness, as it was difficult to make changes in their daily lives. The women conceived anxious about having been ill, which was stressful in itself. When they had pain or different kinds of symptoms, they immediately thought that they were suffering from a second MI. Consequently, there were frequent visits to the emergency department. After being discharged from the CCU, the women found that people in their immediate environment responded differently towards them. Children's or parents' extremely overprotective behaviour stressed them further.

They experienced limitations as a result of the illness which made their previously active life impossible. They now experienced their lives meaningless. Giving up cigarettes affected their daily lives as well as the fact that when they stopped smoking they had problems maintaining their normal weight. The women had used smoking as one way to calm down mentally. They were constantly thinking about the reason for the MI. The younger women in particular thought that only elderly people like their parents or grandparents could suffer an MI. Such thoughts were extremely stressful because it was difficult to get rid of them and they could find no explanation as to why they had suffered an MI.

After discharge from the hospital the women expressed that they wanted to have more support, i.e. psychological and practical support from the community home care service. They described feeling overwhelmed when they returned home to resume

caring for the people around them, and simultaneously tried to carry out recommended lifestyle changes. The women described this as having no one who cared for them, and they felt depressed and lonely. They also expressed frustration with the post-MI rehabilitation programme. The younger women felt frustrated hearing about different kinds of illnesses from others. All the demanding responsibilities were stressful in that they did not have the same strength to carry out everything as before. They were stretched to the limit between their roles of full-time working women and homemakers; they were concerned about how they would manage to resume both their work schedules and their family duties. In addition, for financial reasons, they also experienced stress over the need to return to work too soon after discharge, instead of staying home to recuperate.

Study III

Coping with stress in connection with the MI

Women coped with the stress at the time of the MI by using cogitative actions, social belonging and emotional diversion. Reflection made the women aware of the stress, and gave the emotional diversion. Reflection made the women aware of the stress, and gave them a new insight and helped them to see the kind of situations that created the stress. The women suffered from other diseases and stress related symptoms such as severe headache. It was necessary for them to accept and recognize the stress symptoms to prevent the stress. It was vital for the women to take one day at a time and to devote themselves to the important things in life. Planning made everyday easier, and they were able to avoid stressful events and also learned how to decide priorities in their daily lives. Social belonging and contact with others was beneficial. The women described how the stress was easier to handle when they had someone to talk to about their feelings. It gave them the strength to continue. It was important for them to use sharing events as a way of coping with the stress. They found that meeting and talking with other women with the same experiences of life situations was very supportive. Confirmation by others was essential to the women's wish to be needed and to help others. This was essential, especially for the older women who had been working or taking care of the home their whole life. The women described how they used their own resources to reduce stress. They handled the stress through different kinds of activities. They were able to relax when they were spending time outdoors i.e. working in the garden or doing physical activities. Descriptive categories and conceptions are shown in Table 3.

Table 3. Distribution of descriptive categories and conceptions of the women interviewed at the time of and after a myocardial infarction (MI).

Description categories	Conceptions	At the time of the MI	After MI
Cogitative actions	Reflecting	X	X
	Accepting	X	X
	Planning	X	X
Social belonging	Talking with someone you trust	X	X
	Sharing events	X	X
	Being confirmed	X	X
Emotional diversion	Avoiding	–	X
	Relaxing	X	X

Once the health care professionals in the emergency department had verified the MI, the women struggled with the reality of the diagnosis and with how they could manage their daily lives in the future. To deal with post-MI stress, the women learned a variety of techniques designed to help them get on with their lives while coping with their chronic illness. This involved cogitative action comprising three conceptions: reflecting, accepting and planning. By learning how to reflect on their situation the women were able to see their traumatic life event from a broader life situation. They learned to look for meaning by accepting their new situations. As a result of having an MI, the women reflected on the nature of the change, and learned to adapt to it. Since they were unable to return to their usual household activities, they learned to use reflection in response to the stressor. They also learned to plan for their needs after the MI and carry out those plans. The women had to develop a new way of thinking by means of strategies such as distancing themselves from stressful events and becoming aware of the importance of planning and prioritizing.

The women described how social belonging was important in providing them with stress relief, especially talking with relatives, colleagues and friends. The women were relieved to learn of other people’s similar experiences and recoveries. Talking, sharing concerns and fears with others and receiving confirmation were important ways of coping with stress that they experienced after the MI. In their encounters with health care professionals, the women valued the opportunity to share events. Belonging to a rehabilitation programme as a group member gave them a sense of security. The group members received confirmation from each other as well as from the health-care professionals. Learning that fear and anxiety after an MI are “normal” reactions was reassuring. The older women felt more secure and satisfied with life when they received support from family members. The support they obtained from their surroundings helped them to cope with stress. They were of the opinion that men and women did not talk or share things in the same way.

The women tried to deal with a life situation described as chaotic and sometimes stressful. Their own attempts provided them with new insights. They found different coping strategies, such as physical activity, reading, and gardening activities, useful in distracting them from their condition. They found it difficult to relax, which they described as getting away from the stress. One less positive means of coping was avoidance. The women reasoned that their hearts could not be damaged because they were not put on any form of medication.

Study IV

The women's experiences of an MI – five years later

Two main categories emerged from the analysis: consequences of a myocardial infarction and adjustment to a new life situation (Table 4). The main categories had seven conceptions each. The findings of this study describe the limitations which the MI has caused in the women's lives even five years after the MI.

Table 4. Distribution of descriptive categories and conceptions of the women interviewed five years after a myocardial infarction (MI).

Description categories	Conceptions
Consequences of a myocardial infarction	Fear and anxiety for the future Suffering from other serious illness Medication and secondary effects Rehabilitation Fatigue and other health complaints Fearing another MI Downgrading
Adjustment to a new life situation	Moving forward with difficulties Gratefulness Taking responsibilities for lifestyle changes The recovery process Interaction with family and friends Being aware of the heart Financial stress

The older women conceived that they had poorer physical recovery paths than the younger women. Furthermore, the older women suffered from various co-morbidities such as diabetes, kidney diseases, high blood pressure, stroke and rheumatoid arthritis. The women did not perceive their heart disease as interfering in their daily lives. They were either not bothered by their heart condition, or had other conditions that overshadowed their heart disease. Five years after the MI the women still worried about medication and secondary effects. They suggested that a doctor should have informed them in a better way why they have to take all these drugs. Several of the women described how they experienced a feeling of failure when their body was dependent on drugs, and they wished to reduce these as much as possible. Furthermore, the women said that they were very anxious about all the secondary effects of the drugs that they had to take the rest of their lives. After the first year post-MI the women were not given the opportunity to continue to attend a rehabilitation programme. The women described how they would have liked to have contact with professionals in CHD more than one year after the MI. They said that they still needed support to continue the changes in their daily life. Contact with the rehabilitation programmes depended on where the women lived and also on whether there was a rehabilitation programme. The period after the MI was characterized by struggles with different health problems such as arrhythmia and poor physical fitness. Five years later the women still had serious problems with their health. The most bothersome health complaints were experienced by responders as fatigue and other health complaints i.e. a serious condition with varying degrees of exhaustion, lack of energy and/or tiredness. Lack of energy and milder forms of tiredness were described in terms of need for rest after physical activities or a need to go to bed earlier.

Following acceptance of the diagnosis, the women in early recovery period were motivated to accept responsibility for making lifestyle changes. The women had thoughts about having a new MI. Furthermore, they were grateful and described it as having a second opportunity. The women wanted to move forward in their lives. It was difficult for the women to continue with their lives, although five years had passed since their MI. After the MI they were reminded about their fragile health because they were scared of having another MI. The women described variation over time regarding compliance with suggested lifestyle changes. While it was evident that the women were determined to succeed in undertaking lifestyle changes, the task was more difficult than anticipated. The women changed their lifestyle immediately and some needed time for reflection before they could make the lifestyle changes. They became aware of how they had stressed and tried to change their daily living. The women found it difficult to continue with all the changes. They needed support from health care professionals. The women described how they were aware of having a heart and also how the heart was beating. They described the fear of having a new MI and the consequences of having one again. They were aware of the risk of not surviving a second MI. They had met other patients who had a second MI after five or ten years. The women were scared of the necessity to undergo surgery if they had a new MI.

Study V

Primary health care resources for CHD patients

Only 5% to 10% of the PHCCs had nurses with special education in coronary heart disease and cardiac rehabilitation and 5% had nurses with a special position to take care of these patients. Of all centres 76% had access to a physiotherapist, whereas there were significantly ($p= 0.03$) more public PHCCs (84%) compared to private centres (61%) that had access to a physiotherapist (Fig. 1). The same relation was found regarding access to a dietician; 60% for all centres and 73% for public centres versus 32% for private centres ($p<0.001$) (Fig. 2). There were no statistically significant differences between the offers to men and women, but men (43%) always were offered stress management programmes more often than women (33%). Most (94%) of the PHCCs had no routines to offer socio-economic support to CHD patients and most (90%) answered that there was no need for this kind of support. The majority of the centres (89%) did not evaluate or present results or have any follow-up regarding CHD patients. Furthermore, the majority (91%) of the PHCCs had no cooperation with patient organizations like the Swedish Heart and Lung Association.

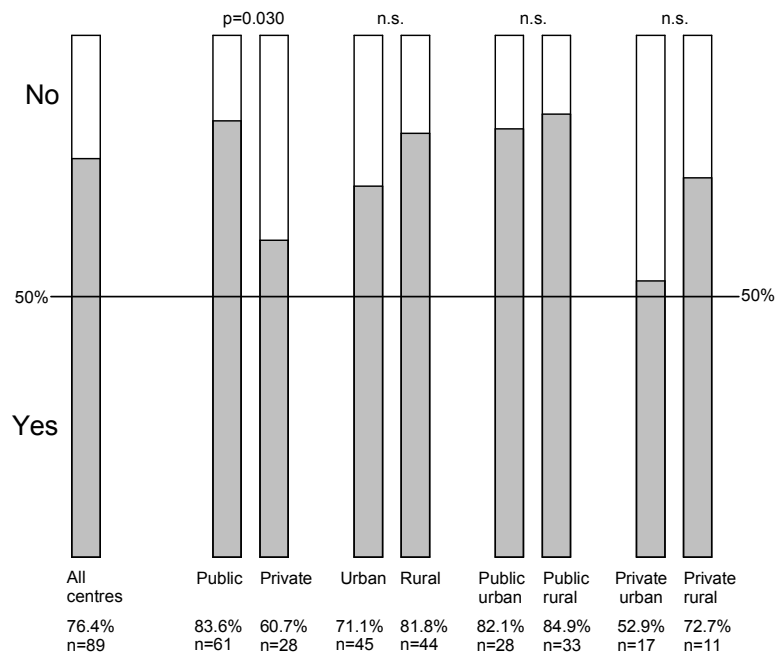


Figure 1. Rate of “Yes” and “No” answers to the question: “Does your primary health care centre have access to a physiotherapist for coronary heart disease patients?” from all centres, main groups and subgroups. The numbers given below the bars are the frequency of “Yes” and n =total number of centres, n.s. = not statistically significant.

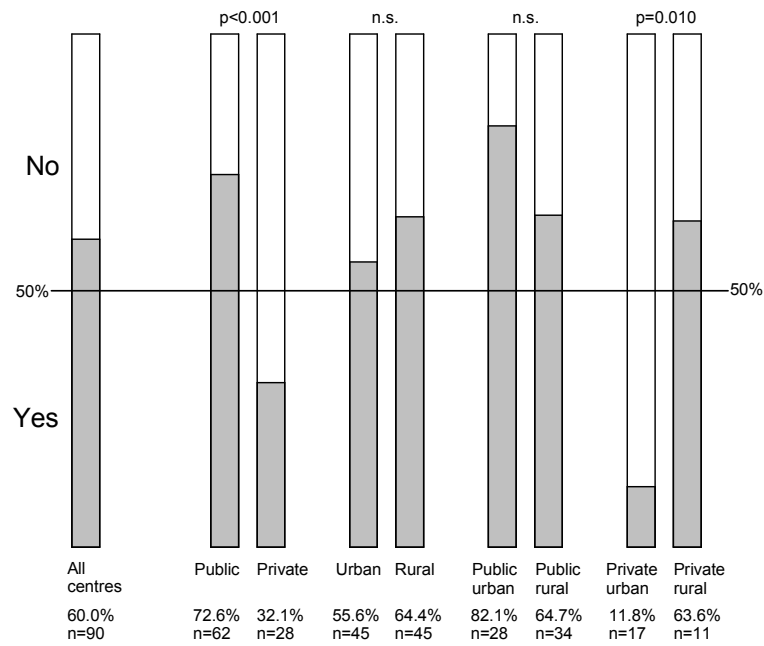


Figure 2. Rate of “Yes” and “No” answers to the question: “Does your primary healthcare centre have access to a dietician for coronary heart disease patients?” from all centres, main groups and subgroups. The numbers given below the bars are the frequency of “Yes” and n=total number of centres, n.s. = not statistically significant.

DISCUSSION

General considerations

Symptoms and delay in seeking medical care at the time of a first MI

The women described their symptoms as difficult to interpret, even if there was a clear history of CHD in the family (I–II). In another study women have described chest-related MI pain as “burning, squeezing, or upper abdominal fullness” rather than chest pain centralized over the sternum [141]. Increased awareness in women that symptoms such as nausea and back pain might be indicative of an evolving MI might assist women to respond more quickly and obtain more timely treatment. In women the clinical signs and symptoms of CHD develop over an average of 8 to 10 years later than in men. Gallagher et al. found that women describe several issues that contribute to a quite complex and multifaceted decision-making process, from symptom onset to treatment-seeking response, which often contributed to delays [142]. Studies I and II show that the women described how they had experienced prodromal symptoms, and the women also presented symptoms such as shortness of breath, unusual tiredness, and anxiety. McSweeney et al. reported that women have experienced prodromal symptoms, the most common symptoms being unusual tiredness or fatigue, shortness of breath, pain in the shoulder blades or upper back and indigestion [143].

The women in the present study hesitated to seek medical care, most commonly because they expected the pain to disappear and attempted to cope with the symptoms. Furthermore, the women tried self-treatment before seeking medical care (I). When people experience symptoms of acute coronary syndrome for the first time, recognition and appropriate action may be more difficult than for subsequent CHD events [144]. Zerwic et al. point out that women seem to delay through responses such as self-care treatment [145]. The women had difficulties making the final decision to seek medical care, because they needed support from family and friends (I). Turesson and co-workers found that the majority contacted a family member, whereas only 3% directly called an ambulance [146]. Other studies have also found that a small proportion of MI patients called for an ambulance as a first response, and this was associated with significantly shorter delay [147;148]. On the other hand, calling or visiting primary health care was associated with significantly increased delay [149]. Women should learn that it is life-saving to seek emergency medical care immediately when suffering from chest pain that can be associated with an MI. Cardiac disease continues to be the number one killer. If a cardiac arrest takes place at home, survival rates are dismal; fewer than 2% were alive after one month [150]. Therefore it is important to make individuals aware of how to handle chest pain and also what delay in seeking medical care can lead to, and that in such situations it is important to call for an ambulance directly.

How women experienced stress in connection with the MI

Study II showed that women of a certain personality type were constantly worrying and anxious about something, often related to the family or working life. It is vital to assess the impact of depressive and anxiety symptoms and disorders that increase cardiac morbidity and mortality in women [151]. According to Bogg et al., women experience greater emotional difficulties and poorer quality of life than men [152]. Women often describe stress in the context of personal relationship and their own personality, characterizing themselves as prone to worry [63]. Women have also admitted delaying symptom assessment and disease management in order to accommodate family needs [117]. It is thus vital to target women and improve their mortality and morbidity following an MI through health promotion [118;153]. Demands on women often include supporting and encouraging their spouse, children or parents [58]. Stress is usually associated with over-stimulation (e.g. having too much to do, an excessive work pace, too much responsibility, etc.). However, stress is also induced by under-stimulation. In study II, the women, especially the older ones, perceived that their daily life was no longer meaningful. According to Roebuck et al. women often suffer from isolation and loneliness after MI [67]. Elderly women's perception of having an MI was described as searching for a diagnosis. They tried to identify the source of the change that had taken place [119]. Exhaustion, in terms of prolonged fatigue and loss of strength or vitality, is conceived as a condition that may arise during the course of chronic stress [154]. Chronic diseases also increase stress level, resulting in limitations in daily life, and the women in the present study suffered from chronic diseases, e.g. diabetes, severe headache and fatigue (II and IV). These patients have to use different strategies, such as learning to recognize the symptoms and slowing down (II–III). It is essential to bear in mind that stress in women's life differs, depending on whether they are working and have a family or if they are older, retired or living alone (II). It is possible that women may be less likely to respond to health messages about CHD due to its image as a male disease [118]. It is therefore vital to inform the public in all age groups that CHD is the number one cause of death not only for men but also for women. Patient education should target all age groups.

Furthermore, study II showed that the women had extensive responsibility for relatives such as their partner and children. Previous studies indicate that women with family and professional demands may have a higher stress level, leading to poorer health outcome [103]. Women who take care of an ill or disabled spouse are at greater risk of CHD [109]. Women's traditional responsibility for the home and family leads to stress due to conflicting roles and excessive work pressure, which will become an even greater problem in the future. In extreme cases, this daily stress can lead to social and emotional exhaustion. The women reported that negative life events increased the risk of factors triggering an MI (II). Möller et al. found that the degree of importance attributed to work-related life events is a risk factor for MI, although there was no evidence that an accumulation of stressful life events increases the risk of MI [98]. It is therefore necessary to conduct further studies on life events as a risk factor, and more women are working outside the home than was the case in previous generations. Despite this, women continue to spend more time carrying out

household tasks than men do. The women perceived that they were stretched to the limit due to the conflict between their private and professional lives (II–IV). A study by Balog et al. described the family sphere rather than work as the main source of daily stress. Nurses must support women in expressing their needs and taking greater care of themselves [102].

The women experienced the same pattern of stress after the MI as before. Their life situation was described as stressful, both during hospitalization and after discharge from the CCU (II). The fear of having another MI was ever present. Even five years after the MI the women feared another MI. Anxiety and stress were sometimes expressed physically as a similar experience to having another MI, which resulted in a visit to the emergency department (II, IV). The time after discharge from hospital is stressful, and it has been shown that a significant amount of patients experience continued anxiety [91]. In the present study the women perceived a high level of stress after discharge from hospital due to difficulties in adapting to the new situation rather than fear of the disease itself (II, III). It was difficult for the women to adjust, as they were used to taking care of the family and being in paid employment (II, IV). King et al. found that women admitted to hospital for cardiac surgery continued to provide care for relatives. It is vital that women try to adjust and accept the fact that they have been ill and learn to accept the necessary lifestyle changes [155].

Study I showed that after discharge from the hospital, the relatives tended to be over-protective, which led the women to experience life as meaningless and to feel anger and frustration. Surviving an MI is a major life event for both patients and their spouses [9]. Overprotective behaviour is often a dilemma after illness. The patients and their family need support and help to cope with the new situation. This is in line with Condon and McCarthy, who revealed that overprotection by family members is a source of frustration and aggravation [156]. MI patients must make the recommended lifestyle changes in order to prevent a second MI, which involves a lifelong commitment. The illness experience is perceived as both stressful and frightening. Trying to make all the lifestyle changes immediately after discharge also creates stress.

Women in the present study (III) described that they were constantly preoccupied with thoughts about the illness. They both cried and became angry as a result of their condition and tried to find an explanation as to why it happened to them. Bergman and Berterö found that disease is always a reminder that life is fragile and finite [157]. Reducing emotional distress may improve the prognosis in CHD [158]. After discharge the women stated that no one cared for them. They described how they lacked strength and needed support and help in daily life, which was especially true for older women who were living alone. The younger women were frustrated with the rehabilitation programme and complained that the majority of the participants were older and tended to discuss different kinds of illnesses (I). Women often decline to attend rehabilitation programmes, in spite of the fact that they experience difficulties with lifestyle changes [125;159]. Boudreau found that the two greatest barriers to health-promoting behaviour are family obligations and lack of time [160].

There seems to be a gap between what health care professionals consider vital for the patient in the recovery process and what the patient considers important [60]. Nurses who deal with an increasingly aged and chronically ill population will need to develop strategies that allow them to focus on women's needs, which may be different from those of men [161]. It is necessary for nurses to learn how to meet with and listen to these women in order to offer them adequate health promotion and rehabilitation measures based on an understanding of their experiences as patients.

Coping with stress in connection with the MI

Lazarus has pointed out that coping strategies have at least two main functions to resolve the problem causing the stress. One main function is emotion-focused coping aimed at reducing or managing the negative emotions caused by the stress. Another main function is problem-focused coping, which includes active efforts directed at solving or minimizing the sources of stress [78]. Different kinds of coping strategies were mentioned, for example cogitative actions and social belonging. The women employed cogitative actions to cope with the stress, which helped them to change their daily life by means of practical things. They became aware of how to make realistic plans, and prioritizing was one way of preventing stress (III).

In study III the women expressed the importance of having a trusted person such as a relative, friend or colleague, with whom they could talk. This is in line with the definition of emotional support presented by Hous, which involves the provision of care, empathy, love and trust [121]. Social support has been found to be an important determinant of health outcomes while lack of social support is associated with increased mortality and morbidity [162]. When they have problems, women are more likely than men to turn to others in their social network for help [163]. In study III the women living alone found support and help from other women in the same situation. Women's health education can be complemented by sharing experiences with other women in similar circumstances (III). Group settings are common in health education, especially support groups and groups based on information transfer. Lee et al. proposed that health education should be viewed as an exchange of knowledge about health and health behaviours. When they assumed responsibility for something, the women wished to receive confirmation from both health care professionals and relatives [164].

One way of reducing stress was to use their own resources and to do something other than work or family tasks. The women reported that reading or participating in physical activities was relaxing and helped them to think about something else (III). Exercise training, for example, has been shown to be effective in reducing stress among patients with major depressive disorder [165]. From a nursing perspective it is important to develop effective measures to deal with stress based on participation, such as a stress management programme comprising either individual or group sessions [166-168].

Patients who have suffered an MI have to cope with and adapt to lifestyle changes in order to improve their long-term recovery and quality of life. The women had to make plans and learn what they could or could not do after their MI (III, VI). The findings in study II highlight the fact that recovery involves time for reflection and learning how to break tasks down into manageable parts. Tobin found that women who were unable to make adjustments had difficulties regaining a sense of normality [169]. The women in the present studies (III, IV) accepted the need for change and realized that the MI had given them a new perspective on life. This is in line with Delmar et al., who showed that patients suffering from chronic illness gradually discovered a new way of living and thereby new meaning in life [170]. The women in the present studies (III, IV) used their social network and the older respondents required more practical help, while the younger ones needed more emotional support (III, IV). Study III underlines the importance the women attributed to receiving support by talking to someone they trusted. Blom et al. reported that marital stress had an impact on social relations among middle-aged women with CHD [108]. The women in the present study (III) wanted to attend some kind of support group where they could talk and listen to other women who were or had been in the same situation. This is in line with Lee and Garvin, who found that individuals tended to pay heed to and act upon knowledge gained from their own experience and that of lay persons [164]. Social support enhances well-being, motivation and the maintenance of positive health patterns [126]. Condon and McCarthy reported that, while stress is the most commonly described contributory factor, subjects are often vague regarding stress management and they lack specific knowledge about how to cope [156]. After hospital discharge the women valued the opportunity to participate in various activities, as it took their mind off their illness and made them think of other things, which they described as a relaxation (III). Helpard found that housekeeping helped women to cope with their illness and gave them an identity and self-esteem [171]. Avoidance was also used to handle the illness, and the women were often filled with anger and denial (III). According to O'Neill and Morrow, using avoidance is related to greater symptom severity [163]. A study by Kristofferzon et al. showed that women tend to use evasive coping strategies one month after MI, which may contribute to an increase in physical and psychological problems. The women are preoccupied with the attempt to minimize their MI [172]. Women have a truly distinct outlook on recovery, and view their MI as a serious event that disrupts their family and social life [169]. Educational programmes aimed at increasing awareness of the impact of CHD on women need to be provided.

Women's experience of MI five years later

Study IV showed that the women were moving forward with difficulties. Fatigue and other health complaints were among the most common symptoms five years after the MI and were cited as the cause of inability to continue with the usual routines and lifestyle changes. Similarly, other authors have reported that weakness and fatigue are common in elderly women when they resume activities after MI [173;174]. Research indicates that women stop or change the pace of activity to accommodate their fatigue. Increasing physical activity can have a cascading effect on other risk factors; it can modify stress, prevent functional decline, and improve quality of life

[175]. However one of the most frequently reported barriers to participation in physical activity is fatigue [174]. Five years after the MI the women in the present study (IV) still experienced tiredness; they experienced fear and anxiety for the future and this influenced their daily life. The women were aware of their heart and felt it beating and they were afraid of another MI. The condition for some of the women was bothersome.

Findings in studies II and IV indicate that women who suffer an MI also very often have other health problems to deal with and therefore require a great deal of support from health care professionals. Support from the health care only during the first year after their first MI is not enough (IV). The women in the present study described how they had difficulties interpreting and understanding symptoms and link the symptoms to CHD or to a panic attack (I–IV). The women should benefit from the possibility to visit or consult professionals in primary health care with knowledge of CHD.

The primary health care centre resources

Many of the participants in the present study (IV) would have needed, and preferred, the possibility of consultations with e.g. a nurse at an outpatient clinic as a long-term follow-up option. Primary health care teams have a good opportunity to make women aware of cardiac risks, and nurses in particular can play an extremely important role in both primary (early detection) and secondary disease prevention. The education level regarding CHD disease and MI patients among the health care professionals at the PHCCs is an important issue. Nurses should inform women about the importance of seeking prompt treatment, discuss health problems and guide them regarding lifestyle changes [172]. By using a comprehensive cardiac rehabilitation including assessment, education, discussion, follow-up and, if needed, referrals to other disciplines, it is possible to reduce the risk of CHD and prevent future cardiac events [176]. Nurse-led outpatient heart-failure clinics have shown increased patient satisfaction and reduction in mortality and re-admission [177]. As the women in study IV requested better contact with PHCC, we decided to scrutinize the resources for these patients at the PHCCs.

Study V showed that the PHCCs had very few nurses and physicians with special education for coronary heart disease, cardiac rehabilitation and heart failure. Although cardiac diseases are the reason for death for most people in our country, the PHCCs have not allocated special resources for these patients. It is also important to stress the need for physiotherapists and dieticians who are well educated and updated. The vast majority (94%) of the PHCCs had no routines for offering socio-economic support to the CHD patients, and in the opinion of the staff (90%) there was no need for socio-economic support for these patients. It is well documented that patients with low income have an increased risk of mortality due to CHD [17;178]. Furthermore, study IV showed that MI patients were burdened with financial stress even five years after the MI.

One study has shown that the physical condition of the patients is a reason for not modifying health status [50]. Studies also report that women have difficulties participating in physical activities, often because they are older and experience fatigue [174;179]. Concerning the long-term follow-up after an MI, the patients have to take contact with the PHCC, but it will be almost impossible to know where to find information about a PHCC with well-educated staff.

The majority of the investigated PHCCs had no cooperation with patient organizations. One idea for the PHCC could be to offer group sessions for patients with CHD and also have cooperation with patient organizations like the Swedish Heart and Lung Association.

Cardiac rehabilitation programmes are proven treatment for those with CHD, yet less than one-quarter of those who are eligible actually attend these programmes, with transportation access as the greatest barrier [180]. The use of computers in patient education has developed during the last few decades and the accessibility of computers has increased rapidly. There are educational tools available both over the Internet and through multimedia software. It has been shown that elderly patients can manage to run computer programmes without previous experience [181]. Zutz et al. developed an Internet-based rehabilitation programme for patients with CHD at a distance. After 12 weeks, those using the Internet programme underwent improvements in exercise capacity, weekly physical activity, and exercise-specific self-efficacy [180]. A disadvantage of computer-based education is that some of the personal interaction with health care professionals in the education situation is lost [181]. Computers can never replace a personal meeting with a specialty in the actual disease. Since the number of PHCCs is increasing, it would be a major achievement for CHD patients if certain PHCCs specialized in cardiac diseases.

Methodological considerations

Methodological issues in studies I–IV

In qualitative research the concepts of *credibility*, *dependability*, *transferability* and *confirmability* have been used to describe various aspects of trustworthiness [182;183]. *Credibility* refers to confidence in how well the data and analysis process address the focus of the research [183]. One of the first questions related to credibility arises when deciding on the focus of the study, selecting a context, choosing participants and agreeing on a data collection approach. Choosing participants with differing experiences increases the possibility of shedding light on the research questions from a variety of perspectives [184]. In the present thesis, participants of different ages, civil status, and number of children and level of education contributed to rich variation in the phenomenon under study. Selecting the most appropriate data collection method and the amount of data is also important for establishing credibility. The phenomenographic approach, which employs semi-structured interviews as the method of data collection, was chosen in order to describe how women perceive their situation (II, III, and IV). Moreover the rich

material further strengthened the credibility. The interviewer tried to create a positive atmosphere, in order to encourage participants to express their personal opinions, as this was important for the data collection. For study I, content analysis was chosen to describe how the women described their symptoms and delay seeking acute care.

Another aspect of trustworthiness is *dependability*. According to Lincoln and Guba dependability “seeks means for taking into account both factors for phenomenal or design induced changes”, that is, the degree to which data change over time and any adjustments introduced by the researcher in the course of the analysis process [182]. There is a risk of inconsistency when dealing with a large amount of data and a long-drawn-out data collection period. It is important to question all participants about the same areas. Interview and observation are an evolving process that provides new insight into the phenomenon under study, and can influence follow-up questions or narrow the focus of observation. In this thesis the researcher remained close to the original meaning and context, referring back to the tape recordings and transcripts of the interviews during the analysis and writing process. The extent to which judgements about similarities and differences in content are consistent over time can be addressed by means of an open discussion in the research group.

Transferability refers to the extent to which the findings can be transferred to other settings or groups [183]. Transferability thus concerns the generalizability and applicability of the data. To facilitate transferability, it is important to provide a clear and distinct description of culture and context, selection and participant characteristics, the data collection and analysis process. A rich and vigorous presentation of the findings together with appropriate quotations will also enhance transferability. The findings in the present thesis can be transferred to similar clinical settings related to women’s experience of an MI. The authors can make suggestions about transferability, but it is the reader who must decide whether or not the findings are transferable to another context.

Confirmability, which is synonymous with objectivity and neutrality, refers to the objectivity of data [182] and is concerned with establishing that interpretations of the findings are not figments of the imagination of the authors, but clearly derived from the data. In this thesis, the authors read the interviews and carried out analyses independently of each other, which also involved the selection of the quotations. Negotiated consensus was used to establish the confirmability, which involved discussing the suggestions related to the classification of categories and conceptions until agreement was reached between the authors and experts involved in the analysis process [137].

Methodological issues in study V

Both closed and open-ended questions were examined by an expert panel. Face validity refers to whether the instrument appears to be measuring the appropriate construct [185]. The construction of the items was strengthened by face validity, which included two general practitioners and four primary health care nurses. The involvement of all of these experts strengthened the relevance of the original items,

the face validity resulted in adjustments of the questions. Furthermore, this made it possible to enhance the quality of the data by changing the formulation of some questions. Content validity was supported by the fact that the items were based on experiences from previous studies and a literature review. Some limitations of the present study have to be considered. The low response rate can be explained by the reorganization process of the centres. Furthermore, some of the managers at the PHCCs had responsibilities for more than one centre so they felt that they did not have the time to answer the questionnaire. Another limitation could be that only a small proportion of the PHCCs in Sweden were studied, but we assume that the results can be applied to the whole country when patient-driven and market-oriented policies may have an impact on primary health care.

FURTHER RESEARCH

- Many women had early symptoms of MI such as tiredness, breathing and sleeping difficulties. Women and health-care professionals need to become more aware of specific female symptomatology and MI presentation. More studies are needed in which women report their early symptoms in order to become more aware of atypical symptoms.
- The findings in this thesis raise further questions about the differences between younger and older women in terms of age-specific health management of problems encountered by women following an MI. Large-scale studies regarding how elderly women cope with stress after an MI are necessary.
- Women have a low attendance rate in rehabilitation programmes, and therefore it is important to explore how their work and family obligations interfere with attendance. More studies are needed in order to perform qualitative analyses that explore and describe women's needs in relation to rehabilitation programmes.
- Interventions, including stress management programmes for women with CHD, need further evaluation. One area for research could be to evaluate and compare special cardiac rehabilitation groups for women with general groups comprising both men and women.
- To start groups for patients who have suffered from CHD at the PHCCS and to focus on long-term prevention. Also to do interventions regarding rehabilitation programmes at the PHCC, and compare public PHCCs with private ones.

CLINICAL IMPLICATIONS

The most vital implication for practice is to have knowledge and understanding of women's experiences both at the time of and after an MI in order to properly assess, plan, implement and evaluate nursing care. An understanding of this phenomenon can help the health care professionals at the Coronary Care Unit, rehabilitation nurses and primary healthcare to support these women and their partners in their efforts to adapt to their daily lives both before and after an MI.

An important task for nurses is to assess the coping resources of these women as well as assisting and supporting them in their efforts.

It is necessary to provide information both to general public and to employers about how to prevent CHD in women and how to prevent women from suffering a second MI. It is essential that the way in which women perceive their life situation after an MI is communicated to the primary and occupational health care services.

This thesis highlights the need for development of primary care services and more individualized rehabilitation programmes for women, as well as the need to provide information about stress and CHD. Furthermore, the thesis shows how MI patients need long-term support and follow-up.

Cardiac rehabilitation programmes are proven treatment for those with CHD, yet less than one-quarter of those who are eligible actually attend these programmes, with transportation access as the greatest barrier. The accessibility of personal computers has increased rapidly and they can be used systematically in patient education for CHD and other diseases.

In the future the private PHCCs will increase and it will be important for PHCCs to choose what kind of speciality they want to have. This way makes it possible for the patients to see that a special PHCC can offer highly qualified disease prevention, for example to prevent CHD.

CONCLUSIONS

Qualitative interviews followed by phenomenographic analysis are an appropriate means of contributing to a deeper understanding of human experiences and how illness affects lives. Qualitative findings cannot be generalized, but can nevertheless provide a clear picture of women's experiences following an MI. Furthermore, interviews and a qualitative method can be used to describe why women delay seeking acute treatment and also how they experience symptoms. There is a lack of studies on women regarding long-term follow-up after an MI, solely with focus on how they experience their daily life. This thesis points out what kind of resources the primary care centres can offer in the long term after an MI.

- The women described how the symptoms increased in severity and occurred over a period of weeks or a month before they acted on them. The women had prodromal symptoms with fatigue or discomfort in the chest before the MI.
- Women described stress as a personal trait. They were afraid of losing control over their lives, both in the family and in their job. High demands were exhausting and stressful, and the stress had been present for a long time.
- Women had demanding responsibilities due to taking care of their children or, in the case of older women, were looking after a sick relative. The demands were so great that they had difficulties slowing down, despite the fact that they suffered from extreme tiredness and sleep problems.
- The stress continued or accelerated after the MI, due to the need to make lifestyle changes such as giving up smoking and starting to do regular exercise. They constantly worried about having a second MI.
- Women handled stress by talking to someone whom they trusted, which they described as togetherness with relatives, friends and colleagues. Furthermore it was important for the women to use their own resources to cope with the stress. They needed to do something with their hands such as gardening.
- Even five years after the MI the women experienced difficulties with their life situation, but they also felt that they were given a second chance, that they had survived the MI.
- A majority of the PHCCs had staff with low educational level regarding CHD and cardiac rehabilitation.
- Most of the PHCCs had no routines to offer socio-economic support to CHD patients, and most answered that there was no need for this kind of support.

SUMMARY IN SWEDISH

Svensk sammanfattning

Hjärt- och kärlsjukdomar är idag den vanligaste dödsorsaken i stora delar av världen för både män och kvinnor. I Sverige är hjärtinfarkt den vanligaste dödsorsaken för kvinnor över 55 år och för män över 45 år. Det vill säga kvinnor drabbas cirka 10 år senare. Tidigare forskning har baserats i huvudsak på män varvid forskning på kvinnor med hjärt- och kärlsjukdomar har försumrats.

Det finns ett flertal riskfaktorer för att utveckla en hjärtinfarkt. De vanligaste och mest välkända riskfaktorerna är ärftlighet, diabetes, hypertoni, men även livsstilsfaktorer som övervikt, bristande fysisk aktivitet, rökning och stress är bidragande faktorer. De senaste decenniernas forskning har dessutom visat att även psykosociala faktorer har betydelse för risken att drabbas av hjärtinfarkt. Hur dessa riskfaktorer påverkar individen ser olika ut för män och kvinnor.

Kvinnors situation i samhället har förändrats. Kvinnor förvärvsarbetar i samma omfattning som män i dagens svenska samhälle. Trots detta så ansvarar kvinnor fortfarande i större omfattning för hemmet och familjen än männen. Studier visar att kvinnors upplevelse av stress huvudsakligen kommer ifrån arbetet i hemmet än från förvärvsarbetet. Inom omvårdnadsprofessionen är det av stor vikt att förebygga riskfaktorer och att försöka få till stånd en livsstilsförändring för att förhindra hjärt- och kärlsjukdomar. Människor som drabbas av hjärt- och kärlsjukdomar lever under ett livshotande tillstånd och detta ger inte bara fysiska besvär utan också emotionell påverkan. Hur detta påverkar individen kan bero på förmågan att hantera stresstillstånd i det dagliga livet.

Det övergripande syftet i denna avhandling var att beskriva och undersöka kvinnors erfarenhet av att drabbas av en hjärtinfarkt. I studie II, III och IV användes ett strategiskt urval utifrån ålder, antal barn, utbildningsnivå och civil status. Intervjuer genomfördes vid två tillfällen. Den första intervjun genomfördes på intensivvårdsavdelningen på andra eller tredje dagen efter insjuknandet. Den andra intervjun på samma kvinnor genomfördes efter fyra, sex eller tio månader efter insjuknandet. Vid första intervjun deltog 20 kvinnor och vid andra 14 kvinnor. Studie IV genomfördes fem år efter insjuknandet i hjärtinfarkt. Studie III, III och IV har en fenomenografisk ansats som är en explorativ och beskrivande kvalitativ metod. Studie I genomfördes på intensivvårdsavdelningen och har innehållsanalys som metod. Studie V har en kvantitativ ansats med ett frågeformulär som utarbetades av författarna med inspiration från andra studier; detta omfattade 26 frågor. Frågeformuläret skickades med post till samtliga vårdcentraler i Skåne.

Första studien beskriver hur kvinnorna upplevde sina symtom i samband med insjuknandet. Kvinnorna hade svårt att inse att symtomen hade koppling till hjärtinfarkt. Det berodde på att symtomen inte var vad de upplevde som typiska för hjärtinfarkt. Vidare hade de svårt att inse att de skulle kunna drabbas av hjärt- och kärlsjukdom. Kvinnorna hade också upplevt en förändring i sitt hälsotillstånd en tid

innan hjärtinfarkten; de upplevde trötthet och en viss obehagskänsla i bröstet. De beskrev smärtan som tryck över bröstet och fastän det var svårt att hantera smärtan ville kvinnorna stanna hemma så länge som möjligt och hoppades på att smärtan skulle försvinna. Vidare beskrev kvinnorna hur de försökte med olika strategier för att hantera smärtan istället för att uppsöka hälso- och sjukvården. De var i behov av stöd och hjälp från anhöriga att ta beslutat att söka vård. De upplevde svårigheter att kontakta ambulans och ville hellre själva ombesörja transport till sjukvården.

Den andra studien utmynnade i två beskrivningskategorier av hur kvinnorna uppfattade stress före och efter hjärtinfarkten. Beskrivningskategori: A. Personliga egenskaper och B. Påverkan från miljön: Före hjärtinfarkten uttryckte kvinnorna att de levt under en långvarig press. De beskrev att stressen kom inifrån och att de upplevde en rastlöshet på grund av att behöva ha ständig kontroll över tillvaron och oron att inte räcka till. Kvinnorna uttryckte att de levt under stress en längre tid och att detta berodde på en ständig och långvarig oro för en släkting eller en långvarig konflikt. Vidare uttryckte kvinnorna att just denna ständiga oro och ångest var påfrestande, vilket bidrog till att de aldrig kunde slappna av. De äldre kvinnorna uttryckte att livet hade blivit meningslöst på grund av ensamhet och isolering. Kvinnorna hade också andra kroniska sjukdomar såsom diabetes, reumatoid artrit och de uppfattade att detta också var en utlösande faktor.

Före hjärtinfarkten uttryckte kvinnorna att de inte fick stöd från omgivningen i samband med att de vårdade en släkting. De beskrev att de ensamma tog ansvar för en sjuk anhörig och det uppfattades som stress. Kvinnorna uttryckte att de upplevt en långvarig frustration beroende på påfrestande relationer, vilket beskrevs som en långvarig stress. Kvinnorna uttryckte att de hade stort ansvar för familjen samtidigt som de förvärvsarbetade. De beskrev att det var betungande att ta så mycket ansvar och de hade också svårigheter att sätta gränser för vad de orkade med. Kvinnorna uppfattade också att de tog ett stort ekonomiskt ansvar vilket resulterade i stress.

Efter hjärtinfarkten framkom ytterligare en uppfattning förutom de uppfattningar som identifierades innan hjärtinfarkten. Det dagliga livet förändrades markant efter hjärtinfarkten. Kvinnorna beskrev att de hade en ständig inre rastlöshet p.g.a. att de inte hade styrkan att ha kontrollen över hemmet. Vidare framkom att de upplevde en inre oro som var stressande, en oro över att ha varit allvarligt sjuk, men också en uttalad oro över att få ytterligare en hjärtinfarkt. Detta bidrog till att kvinnorna ofta uppsökte akutmottagning i tron om att de fått en ny hjärtinfarkt, men symtomen berodde ofta på ångest och oro. Kvinnorna beskrev att de anhöriga hade en extremt överbeskyddande attityd. Den överbeskyddande attityden ledde till stress och aggressivitet hos kvinnorna och de uppfattade livet som meningslöst. Livsstilsförändringar var nödvändigt efter hjärtinfarkt för att inte drabbas av en ny hjärtinfarkt. En nödvändighet var att sluta röka. Detta påverkade kvinnorna psykiskt eftersom rökning hade varit ett sätt att hantera sin stress. Kvinnorna var också fyllda av funderingar kring sin sjukdom. De beskrev att de funderade över varför de hade drabbats av hjärtinfarkt. Kvinnorna hade uppfattningen att endast äldre människor

och framförallt män drabbas av hjärtinfarkt. De hade aldrig tänkt tanken att de själva skulle kunna drabbas av en hjärtinfarkt.

Efter hjärtinfarkten uttryckte kvinnorna en stress över att de inte fick tillräckligt med stöd och hjälp från kommunen. Det upplevde också en besvikelse kopplat till rehabiliteringen. Kvinnorna var i varierande åldrar och hade skiftande behov vad det gällde rehabilitering. Efter hjärtinfarkten upplevde kvinnorna stress och oro för hur de skulle orka som tidigare, hur mycket de skulle orka arbeta samt en oro för framtiden. Kvinnorna uttryckte också oro över sin ekonomi och sin arbetskapacitet.

Kvinnorna utvecklade olika sätt att hantera stressen i sitt dagliga liv både före och efter hjärtinfarkten. Den andra studien utmynnade i tre beskrivningskategorier: A. Kognitiva handlingar, B. Social tillhörighet samt C. Emotionell avkoppling. Via reflektion fick de en bättre insikt över situationer som var stressfyllda. Detta resulterade i att de planerade och prioriterade tillvaron på ett bättre sätt och kunde undvika vissa stressituationer. De kvinnor som hade andra kroniska sjukdomar såsom diabetes och reumatism försökte hantera detta genom att lära sig sina gränser och att acceptera sin situation. Socialt stöd var ett värdefullt sätt att hantera stressen i det dagliga livet såsom att tala med någon ex. en arbetskamrat eller släkting. Tala med någon och speciellt med någon som var i samma situation gav kvinnorna nya krafter att kunna gå vidare i livet. Kvinnorna hade också behov att bli bekräftade. De äldre kvinnorna ville känna sig både behövda och bekräftade. När stressen i vardagslivet blev för stor, var ett sätt för kvinnorna att bryta stressen att utnyttja sina egna resurser. Denna förmåga skapade distans till tillvaron och gav en emotionell avkoppling.

Efter hjärtinfarkten använde sig kvinnorna av kognitiva handlingar såsom reflektion, planera och prioritera sin dagliga tillvaro. Kvinnorna hittade så småningom en ny mening med livet och omvärderade sina liv samt anpassade sig till förändringen som sjukdomen hade medfört. Det sociala stödet uppfattades av kvinnorna som viktigt. Att prata med någon var betydelsefullt samt ett sätt att hantera stressen. Det som kvinnorna ansåg som värdefullt var att träffa andra i samma situation, samt att höra att andra erfarit samma oro, stress och ångest efter hjärtinfarkt. Bekräftelse från hälso- och sjukvårdspersonal var viktigt såsom att få feedback från sjuksköterskorna i rehabiliteringsteamet. Efter hemkomsten från sjukhuset var den första tiden kaotisk och kvinnorna hade många funderingar kring hjärtinfarkten. De beskrev att det var nödvändigt att komma ifrån alla dessa tankar kring hjärtinfarkten. Ett sätt var att göra något annat och skingra tankarna såsom med trädgårdsskötsel, eller att läsa en bok. Det var också svårt att ta till sig att de hade drabbats av en allvarlig sjukdom. Kvinnorna använde sig inte sällan av förnekande.

Studie IV beskriver kvinnors upplevelser av hjärtinfarkt fem år senare. Det resulterade i två huvudkategorier: A. Konsekvenser av en hjärtinfarkt och B. Att anpassa sig till en ny livssituation. Kvinnorna upplevde fortfarande att deras livssituation var påverkade av att ha haft en hjärtinfarkt. Eftersom kvinnor oftast är äldre när de drabbas av hjärtinfarkt var det vanligt med olika följsjukdomar och

detta påverkade deras livssituation. Vidare upplevde de att de fortfarande hade olika problem med sin hälsa som var relaterat till sin hjärtinfarkt. De upplevde fortfarande att tillvaron var skör och att det fanns en ständig oro för att få en hjärtinfarkt. Kvinnorna uttryckte också att det var viktigt med fortsatt stöd från hälso- och sjukvården.

Studie V visade på vilka resurser som primärvården kan erbjuda för hjärtinfarkt-patienter. Vad det gällde utbildning för sjuksköterskor inom området hjärt- och kärlsjukdomar, hade 32 % någon form av utbildning. Vidare kunde vårdcentraler inom regionen erbjuda större möjligheter för patienter att ha tillgång till sjukgymnast och dietist i jämförelse med de privata vårdcentralerna. Merparten av vårdcentraler kunde inte erbjuda socioekonomiskt stöd; det samma gällde samarbete med olika frivillig organisationer.

Sammanfattningsvis visar avhandlingen på betydelsen av att se kvinnors livssituation som en helhet för att kunna bidra till att identifiera riskfaktorer och att sätta in preventiva åtgärder på ett tidigt stadium. Avhandlingen speglar betydelsen av att hantera stressituationerna både före och efter sjukdomen. Avhandlingen pekar också på vikten av att utforma individuella rehabiliteringsprogram, samt att det bör finnas riktade rehabiliteringsprogram inom primärvården. Att förstå hur olika patienter hantera stressituationer i samband med en kronisk sjukdom är ett viktigt forskningsområde inom omvårdnad som bör utvecklas ytterligare. En slutsats är att i rehabiliteringsprogram bör det även ingå att utveckla patientens egen förmåga att hantera stress. Det finns ett behov av ett fortsatt och långsiktigt stöd och uppföljning.

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