Life After Myocardial Infarction in Swedish Women and Men

Coping, Social Support and Quality of Life Over the First Year

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Abstract

Aims: The general aim of this thesis was to describe the life situation of women and men during their first year after myocardial infarction (MI) with regard to problems in daily life, how they coped with them, the social support available and the patients’ perceived quality of life (QoL). An additional aim was to examine differences over time and between women and men in coping, social support and QoL. Methods: A consecutive series of 74 women and 97 men were selected 1 month after MI and followed over the first year. A qualitative approach was used to describe experiences of everyday life of 20 women and 19 men from the study group, from the onset of MI through the first months after the event (retrospectively). Focus was on managing problems and support from the network (I). Also experiences at 4 to 6 months and expectations of the future were explored (II). Coping, social support and QoL were compared between women and men both with a cross-sectional (at 1 month; 74 women and 97 men; III) as well as with a longitudinal design (at 1, 4 and 12 months; 60 women and 88 men; IV). Findings: Physical symptoms and emotional distress were the most commonly described problems during the first months after MI. The patients managed the problems by negotiating with themselves, relying on their own capabilities, changing attitudes and behaviour and taking their own decisions. The network was generally supportive but also communication problems were described (I). Many of the patients had not established a stable health condition after 6 months. They managed the consequences of their disease, found a meaning in what had happened, and confidence in the future. The support from their social network encouraged them to move on (II). Women used more evasive and supportive coping than men 1 month after MI. More women perceived support being available from grandchildren and friends and more men from their partners. Compared with men, women rated lower health-related QoL and QoL (III). Coping and social support were stable over time, women used more evasive coping than men and health-related QoL increased for both women and men. (IV). Conclusions: The first month after MI seems to be a vulnerable period especially for women. They had difficulties interpreting their heart symptoms, did not want to bother others with their worries and rated lower QoL than men. Patients redefined normal life, found hopes for the future and women did not demonstrate a poorer QoL profile than men over time.

Keywords: myocardial infarction, women and men, gender differences, problems, coping, social support, quality of life

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'När människan föds
tilldelas hon ett visst antal hjärtslag.
Det gäller att
förvalta dem väl.

*Okänd yogi* '  

*When a person is born*  
she is given a certain amount of heart beats.  
The challenge is  
to dispose them well.

*Unknown yogi* '  

List of original papers

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


II Kristofferzon, M-L., Löfmark, R & Carlsson, M. Going on to a redefined normal life and finding hopes for the future: experiences of Swedish women and men 4 to 6 months after myocardial infarction. (Manuscript).


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Contents

Introduction .....................................................................................................9
  Myocardial infarction .................................................................................9
    Coronary risk factors in women and men ..............................................9
    Diagnosis, treatment and prognosis .....................................................11
    Rehabilitation ......................................................................................12
  Coping ......................................................................................................13
    Coping in women and men after myocardial infarction ......................14
  Social support ...........................................................................................15
    Social support in women and men after myocardial infarction ...........16
  Quality of life ...........................................................................................17
    Quality of life in women and men after myocardial infarction ...........18
  Summary ..................................................................................................19

Aims ..............................................................................................................20

Materials and methods ..................................................................................21
  Design ......................................................................................................21
  Setting ......................................................................................................22
  Subjects ....................................................................................................22
    Study I and II .......................................................................................22
    Study III and IV ...................................................................................23
  Data collection ..........................................................................................26
    Study I and II .......................................................................................26
    Study III and IV ...................................................................................26
  Procedure ..................................................................................................31
    Study I and II .......................................................................................31
    Study III and IV ...................................................................................32
  Ethical considerations ..............................................................................32
  Data analysis ............................................................................................32
    Study I and II .......................................................................................32
    Study III ...............................................................................................33
    Study IV ...............................................................................................33

Summaries of findings ..................................................................................34
  Daily life shortly after myocardial infarction (I) ......................................34
    Threatening ordinary life .....................................................................34
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Struggling for control</td>
<td>35</td>
</tr>
<tr>
<td>The ambiguous network</td>
<td>35</td>
</tr>
<tr>
<td>Present everyday life and expectations of the future (II)</td>
<td>36</td>
</tr>
<tr>
<td>Managing consequences of myocardial infarction</td>
<td>36</td>
</tr>
<tr>
<td>Managing changes in social life</td>
<td>36</td>
</tr>
<tr>
<td>Finding a meaning in what has happened</td>
<td>37</td>
</tr>
<tr>
<td>Gender differences 1 month after myocardial infarction (III)</td>
<td>37</td>
</tr>
<tr>
<td>Coping</td>
<td>37</td>
</tr>
<tr>
<td>Social support</td>
<td>38</td>
</tr>
<tr>
<td>Quality of life</td>
<td>38</td>
</tr>
<tr>
<td>Differences over time and between women and men during the first year (IV)</td>
<td>38</td>
</tr>
<tr>
<td>Coping</td>
<td>39</td>
</tr>
<tr>
<td>Social support</td>
<td>39</td>
</tr>
<tr>
<td>Quality of life</td>
<td>39</td>
</tr>
<tr>
<td>Discussion</td>
<td>46</td>
</tr>
<tr>
<td>Coping with daily life after myocardial infarction</td>
<td>47</td>
</tr>
<tr>
<td>Support from the social network</td>
<td>49</td>
</tr>
<tr>
<td>Quality of life</td>
<td>50</td>
</tr>
<tr>
<td>Living with a chronic illness</td>
<td>52</td>
</tr>
<tr>
<td>Methodological considerations</td>
<td>54</td>
</tr>
<tr>
<td>Design and research perspectives</td>
<td>54</td>
</tr>
<tr>
<td>Data collection</td>
<td>55</td>
</tr>
<tr>
<td>Data analyses</td>
<td>56</td>
</tr>
<tr>
<td>Trustworthiness</td>
<td>56</td>
</tr>
<tr>
<td>Conclusions</td>
<td>59</td>
</tr>
<tr>
<td>Clinical implications</td>
<td>60</td>
</tr>
<tr>
<td>Acknowledgement</td>
<td>61</td>
</tr>
<tr>
<td>Sammanfattning (Summary in Swedish)</td>
<td>63</td>
</tr>
<tr>
<td>References</td>
<td>65</td>
</tr>
</tbody>
</table>
Introduction

Forty-six thousand persons suffered from an acute myocardial infarction (MI) in Sweden in 1999, and 24% of them died before they reached hospital (Stenestrand, 2002). Those who survive an MI must cope with the consequences of this disease, such as disease-related symptoms, treatments and lifestyle changes (Maeland & Havik, 1989; Al-Hassan & Sagr, 2002; Ostergaard Jensen & Petersson, 2003). The first month after an acute MI is a vulnerable period both physically and emotionally (Daly et al., 2000). For many, the cardiac event is traumatic and it may influence their well-being for a significant period of time (Bennett & Connell, 1999). Knowledge of MI patients’ perceptions of coping and social support is important for preparing them for cardiac rehabilitation (Daly et al., 2000).

In a literature review Kristofferzon et al. (2003) found that women who experience an MI have physical and medical disadvantages compared with their male counterparts. In addition, women are often older, more likely to live alone, and more often responsible for household duties than are men. Differences in life situations between women and men may lead to different perceptions of coping, social support and quality of life (QoL). Few studies (Wiklund et al., 1989, 1993; Hildingh et al., 1997; Brink et al., 2002, 2005) have examined differences in coping, social support and QoL between women and men after MI in the Nordic countries, and one study with a longitudinal design has been found (Brink et al., 2005). Therefore the present thesis compares perceptions of coping, social support and QoL between Swedish women and men over the first year after an MI.

Myocardial infarction

Coronary risk factors in women and men

MI is the most common cause of death in Swedish men over 45 years of age and in Swedish women over 55 years of age (Schenck-Gustafsson, 2003). Many risk factors for MI are shared by women and men (Lundberg, 2000), but the disease is manifested 10 - 20 years later in women than in men (Flavell, 1994; Moore, 1995; Graves & Miller, 2003), a difference that is generally believed to be due to protective influences of female reproductive hormones (Flavell, 1994; Schenck-Gustafsson & Al-Khalili, 1998; Lundberg,
Early menopause seems to increase the risk of MI in women (Schenck-Gustafsson & Al-Khalili, 1998; Lundberg, 2000). Family history of an MI by a first-degree relative may be stronger in women compared with men (Arnstein et al., 1996). A Swedish study found that hypercholesterolemia, hypertriglyceridemia, hypertension, overweight, diabetes, physical inactivity, smoking, and job strain were stronger risk factors (higher relative risk) in women than in men (Reuterwall et al., 1999). Also other studies have reported diabetes, hypertension and smoking to be greater risk factors in women (Flavell, 1994; Brett & Madans, 1995; Lundberg et al., 1997; Juutilainen et al., 2004).

Low socio-economic status (e.g. low social class and low education) and job strains have shown to be associated with coronary heart disease in both women and men. These factors may even be of greater importance in women than in men (Brezinka & Kittel, 1995; Wamala et al., 1997, 1999; Orth-Gomér, 1998, Theorell et al., 1998). Low socio-economic status seems to be linked to coronary-prone lifestyle patterns such as smoking, a sedentary lifestyle, higher consumption of sugar and saturated fat and increased stress in both women and men (Brezinka & Kittel, 1995; Wamala et al., 1999). Welin (1995) found that irritability, low social activity, mental job strain and negative life events increased the risk of MI in men and low social activity and mental job strain increased the risk in women. Hallman et al. (2001) found that women were more sensitive than men with regard to psychosocial risk factors for MI such as work content, work load and control, physical and emotional stress reactions, and burn-out. Studies report that 20% to 40% of patients with coronary heart disease show depressive symptoms. It seems to be an independent risk factor both in women and men (Frasure-Smith et al., 1999, 2000; Horsten et al., 2000; Cossette et al., 2001; Graves & Miller, 2003). Studies have also reported more depressive symptoms in women compared with men after a cardiac event (Frasure-Smith et al., 1999, 2000; Horsten et al., 2000; Mendes de Leon et al., 2001; Norrman et al., 2004). Vital exhaustion, a syndrome of unusual fatigue and loss of energy, increased irritability, and depressive symptoms, seems to increase the risk for MI in both women and men (Appels et al., 1993; Claesson et al., 2003), especially in women with a paid job who simultaneously take care of a household which includes children younger than 16 years of age (Appels et al., 1993). Collijn et al. (1995) found that poor structural support (few supportive persons) was associated with an increased risk for MI in women, and suggested that this was associated with vital exhaustion. Relational problems may be a larger risk factor in women and performance anxiety in men (Kortge, 2003). A medium-sized network seems to be more cardiac protective than small or large networks for both women and men and especially for older women, among whom those with a great number of contacts had the highest mortality. The Type-A behaviour pattern has not been found to pre-
dict MI in women and studies in men have produced mixed findings (Orth-Gomér, 1998).

**Diagnosis, treatment and prognosis**

It has been shown to be more problematic to interpret the symptoms and outcomes of diagnostic tests in women than in men with regard to MI (Arnst ein et al., 1996). A study in the United States reported that 95% of the included women (n = 515) experienced prodromal symptoms more than 1 month before the acute MI. The most frequent symptoms were unusual fatigue, sleep disturbance, and shortness of breath (McSweeney et al., 2003). Women’s descriptions of symptoms at the onset of MI differ from that of men’s (Lundberg, 2000; Kristofferzon et al., 2003). Women are more likely than men to report neck, back, jaw, and right shoulder pain, nausea, indigestion, shortness of breath, and fatigue (Albarran et al., 2002; Ćulić et al., 2002; Patel et al., 2004; Chen et al., 2005), but less likely than men to report chest pain and sweating (Ćulić et al., 2002; Chen et al., 2005).

Morbidity and mortality are reported to be higher in women than in men after MI (Greenland et al., 1991; Young & Kahana, 1993; Hamilton & Seidman, 1993; Riegel & Gocka, 1995). Differences in age, risk factors, and treatment account for much of higher short-term and long-term mortality after MI in women compared with men (Brett & Madans, 1995; Nohria et al., 1998; Hanratty et al., 2000; Tjandrawidjaja et al., 2003; Shaw et al., 2004). Another gender difference found by Lundberg (2000) is that men with MI are significantly more often treated in a coronary care unit than are women. Several studies also suggest that women have less access to major diagnostic and therapeutic procedures (Ayanian & Epstein, 1991; Steingart et al., 1991; Dellborg & Swedberg, 1993; Clarke et al., 1994; Deshotels et al., 1995) and have longer delays in hospital treatment than men (Grace et al., 2003; O’Donnell et al., 2005). In contrast, a Swedish study, which examined time-trends in thrombolytics, showed a significant increase in the use of thrombolytic treatment in women and concluded that a gender-gap is no longer apparent (Johanson et al., 1999). Also William et al. (2004) concluded that gender bias in investigations and treatments can be explained by age.

Depression has shown to worsen the prognosis (e.g. cardiac mortality and recurrences) in the short and long-term perspective in patients with coronary heart disease (Frasure-Smith et al., 1999, 2000; Horsten et al., 2000; Graves & Miller, 2003). Marital stress in women with coronary heart disease (MI, and unstable angina) has shown to be associated with increased risk of recurrent coronary event after adjustment for standard risk factors (Orth-Gomér et al., 2000). In addition, Moser et al. (2003) found that women had significantly higher anxiety levels than men during the first 3 days post-MI across a variety of cultures (Australia, South Korea, Japan, England, and the United
States). Mitchell and co-authors (2005) found that women had significantly higher level of depressive symptoms than men before revascularization, but the symptoms decreased to comparable level with men some months after the treatment.

In Sweden, both short and long-term survival after an MI were markedly improved in men between 1985 and 1994 (the Northern Sweden MONICA study), whereas no improvements were observed in women (Peltonen et al., 2000).

Rehabilitation

Cardiac rehabilitation often contains three phases: 1) the inpatient phase, 2) from discharge to 3 months post event, and 3) the rest of the patients’ lives (Day, 2003). Several hospitals in Sweden provide special programmes for cardiac rehabilitation of patients who have experienced an MI. These programmes usually educate patients in secondary prevention against ischemic heart disease together with physical and psychological rehabilitation (Stenesstrand, 2002). These types of programmes with an emphasis on secondary prevention are recommended both in Swedish (Socialstyrelsen, 2004) as well as in international guidelines for treatment of coronary heart disease (Wood, 1998; De Backer et al., 2003).

Although structured cardiac rehabilitation programmes provide good opportunities for secondary prevention interventions, there are many cardiac patients who do not participate in them. Participation rates vary from 7% to 40% (Graves & Miller, 2003; Cottin et al., 2004; Dollard et al., 2004; Johnson et al., 2004; Chan et al., 2005). Reasons stated for low participation have been related to medical contra-indications, financial constraints, geographic availability (Dracup, 1994), transportation problems (Davidson et al., 2003; Pâquet et al., 2005), interference with work (Pâquet et al., 2005), co-morbidities, inconvenient time, and lack of physician’s recommendation. Encouragement from children has proved to be significantly more important for women than men to promote attendance (Davidson et al., 2003).

Fewer women than men attend the programmes (Young & Kahana, 1993; Fridlund, 2000; Graves & Miller, 2003) and women are less likely than men to be referred to cardiac rehabilitation (Brezinka & Kittel, 1995; Abbey & Stewart, 2000; Cottin et al., 2004). In addition, women are less likely to drive a car and more likely to have a dependent spouse and to have a single-parent situation (Brezinka & Kittel, 1995). Traditional programmes with an emphasis on physical aspects may not meet the needs of women; for instance, they may value being able to share their experiences with other women in similar situations more than exercise and relaxation techniques (Davidson et al., 2003). Following clinical observations, Burell and Granlund (2002) have suggested that the psychological and social consequences of experiencing an MI are different for women and men. They
found that in gender-mixed groups it was sometimes difficult to pay enough attention to the problems of the women such as low self-esteem, family-related stress, and severe life events. Women withheld their own reactions and opinions and were supportive of the men in the group. Thus they used ingrained gender role behaviour (caring for others) and minimized their own needs. A pilot study with a treatment-group-only design, including only women with coronary heart disease, showed promising positive impact on self-rated stress, vital exhaustion, and QoL after 1 year of treatment. This result was confirmed for self-rated stress and vital exhaustion in women with coronary heart disease in a randomized controlled trial (Claesson et al., 2005). The cognitive-behavioural intervention programme included managing anger and medical symptoms, coping with anxiety and depression, enhancing self-confidence and self-efficacy, improving communication, discussing life values and handling social roles (Burell & Granlund, 2002; Claesson et al. 2005). Mendes de Leon et al. (2001) found that women had higher levels of depression and reported lower levels of social support after MI than men and concluded that interventions may need to take account of the specific needs of women and men.

Pâquet et al. (2005) found that cardiac patients wanted to focus more on stress management and better knowledge of their limits than on lifestyle modifications.

In sum, the impact of coronary heart disease seems to be as important in women as in men and compared with men, women who experience an MI may have some disadvantages with respect to coronary risk factors, getting a diagnosis, treatment, prognosis, and cardiac rehabilitation.

Coping

Stress is the condition or circumstances with which a person might have to cope, and coping is a response that aims to reduce the level of stress (Keil, 2004). Lazarus and Folkman (1984) have made a distinction between coping as a trait and coping as a process. Coping as a trait is regarded as a part of a person’s character, which predisposes him or her to react in certain ways across different types of stressful situations and over time. Coping as a process is defined as ‘… constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.’ (p. 178). Coping strategies, such as seeking help, learning new skills, and venting anger are examples of the cognitive and behavioural efforts a person uses in response to a stressor. These strategies are divided into two categories according to their functions: (1) problem-focused, in which a person tries to change her/his situation, and (2) emotion-focused, in which a person tries to regulate the emotions caused by the situation. The revised model of Lazarus and Folkman’s stress and
coping model (Folkman, 1997) includes meaning-based coping. These coping processes can include positive reappraisal, which refers to cognitive strategies through which a person finds meaning by interpreting the situation in a positive light. This type of coping is related to positive emotions, and involves strategies where the person finds a redeeming value in a loss, new or closer relationships with others, and what to prioritize or not. A relationship between finding a positive meaning and psychological well-being has been found in a variety of contexts, including heart attack.

Coyne and Gottlieb (1996) argue that the definition of coping as a process does not cover its full range as it excludes important dimensions such as anticipatory coping and habitual behaviour (similar to a trait). For instance, patients with congestive heart failure may anticipate and avoid complications by carefully regulating their diet, fluid intake and exercise. The authors suggest that patients with a chronic disease may develop habitual behaviour over time.

Conceptual and methodological problems in coping research have been described by several authors (Lazarus, 1993; Coyne & Gottlieb, 1996; Parker & Endler, 1996; Suls et al., 1996). Yet, no consensus of the best way to conceptualize and measure coping exists (Suls et al., 1996). Both personality (trait) and situational (process) variables have been found to participate in specific coping responses (Parker & Endler, 1996). To combine both approaches may advance research in coping (Lazarus, 1993; Parker & Endler, 1996).

Coping in women and men after myocardial infarction

Toth (1993) found that women and men experience similar levels of stress during hospital discharge after MI. Some studies reported that women use more coping strategies than men, including problem-focused, emotion-focused and avoidance strategies (Martin & Lee, 1992; Bogg et al., 2000). Other studies did not find any gender differences in coping (Daly et al., 2000; Brink et al., 2002). Also qualitative studies have described that women use a variety of coping strategies, both problem-focused and emotion-focused (Dempsey et al., 1995; LaCharity, 1997, 1999; Helpard & Meagher-Stewart, 1998; Sutherland & Jensen, 2000; Svedlund & Axellson, 2000; Svedlund et al., 2001).

Several studies found that women minimize the impact of their disease (Johnson & Morse, 1990; Dempsey et al., 1995; Helpard & Meagher-Stewart, 1998; Sutherland & Jensen, 2000) and tend to delay seeking treatment, often because they do not want to bother others with their health problems (Schmidt & Borsch, 1990; Dempsey et al., 1995; Meischke et al., 1995; Rankin, 1995; Foster & Mallik, 1998; LaCharity, 1999). Incongruent findings of gender differences in pre-hospital delay time at the onset of MI have been reported. Some studies found significantly longer delays in women.
compared with men (Schmidt & Borsch, 1990; Walsh et al., 2004), whereas others did not find any gender differences (Grace et al., 2003; Johnson Zerwic et al., 2003).

Household activities seemed to be important to women and aided their recovery (Helpard & Meagher-Stewart, 1998). They did not involve the family in lifestyle changes, which would diminish their workload in the home (Johnson & Morse, 1990). Women resumed household duties early in their recovery, which could increase the risk of complications (Johnson & Morse, 1990; Jenson et al., 2003). Benson et al. (1997) reported that women experience tensions between their social roles (wife, mother, worker, protector) and between needed support and a wish to be independent.

Men were more likely to involve their spouses in their recovery and rest while at home. Resuming work and keeping physically fit were important to them (Johnson & Morse, 1990). White (1999) found that the less chest pain a man had after MI, the more difficulties he had with restrictions and acknowledging the importance of lifestyle changes and cardiac rehabilitation. Evasive coping (e.g., disengagement and denial) has shown to be associated with anxiety, depression and physical limitations in men (Bennett & Connell, 1999). Personal coping resources (e.g., mastery and self-esteem) were stronger predictors of emotional and cognitive readjustments in men who had experienced an MI than were instrumental coping resources (e.g., education and socio-economic status; Ben-Sira & Eliezer, 1990). Repressive coping strategies post-MI may have a negative impact on survival both in women and men (Frasure-Smith et al., 2002).

In the present thesis, the Jalowiec coping scale (JCS-60; Jalowiec, 1988) has been used to assess coping. The JCS-60 is derived from the stress and coping theory of Lazarus and Folkman (1984), which describes coping as a process. The JCS-60 was chosen because it would be useful for repeated measuring.

Social support

The literature has not produced a consensus regarding a theoretical or empirical definition of social support (House et al., 1988). Terms like social network, social relationships, social support, social ties, and social activity have been used to refer to the same phenomenon, viz the existence, number, and frequency of social relationships. Social network refers to the structural aspect of a person’s relationships and social support refers to the function of such relationships (House et al., 1988; Antonucci & Johnson, 1994; Sarason & Sarason, 1994). Social support is one of three important qualities of social relationships. The other two are relational demands/conflicts and social regulation/control. Social support is seen as a positive aspect of the relationship,
which may promote health. Relational conflicts refer to the negative aspects of relationships that may damage health (House et al., 1988).

Potential forms of social support, have been described by House and Kahn (1985) as emotional support (esteem, affect, trust, concern, listening), appraisal support (affirmation, feedback, social comparison), informational support (advice, suggestion, directive, information), and instrumental support (practical aid, money, labour, time, modifying environment).

Schreurs and de Rijder (1997) have described four ways of relating social support to coping: as a coping strategy, as a coping resource, as a consequence of coping, or as fully integrated into a coping process of a social system.

Social support measures can be divided into three categories: (1) networks, (2) support actual received, and (3) perceived available support (Sarason & Sarason, 1994) Social support has been found to have a positive influence on the cardiac rehabilitation process (Bramwell, 1990; Rodeman et al., 1995). Moser (1994) reported that cardiac patients with a low level of social support are at risk for further cardiac events and decreased physical and psychological well-being during recovery.

Social support in women and men after myocardial infarction

Regarding informational support, women received less information about cardiac disease and rehabilitation from caregivers compared with men (Hamilton & Seidman, 1993; Young & Kahana, 1993; Hildingh et al., 1997; LaCharity, 1999). Hildingh et al. (1997) found that the need for information was higher in men than in women. In another study (LaCharity, 1997) women reported lack of support from spouses because of communication problems.

With regard to instrumental support, women received less assistance with household duties from informal caregivers than did men up to 1 year after an MI (Hamilton & Seidman, 1993; Young & Kahana, 1993; Aish, 1996; Rose et al., 1996), which may affect their recovery (Abbey & Stewart, 2000). Bennett and Connell (1999) found that the more instrumental support the men received, the more physical limitations they reported.

With respect to emotional support, Mendes de Leon et al. (2001) found that women experienced lower levels of available support compared with men. In contrast, other studies have reported that women receive more emotional support than men 1 and 4 months after MI (Riegel & Gocka, 1995) and they are satisfied with the emotional support from family and friends (Helpard & Meagher-Stewart, 1998; LaCharity, 1999). More women than men have reported lack of support from their spouses (Hildingh et al., 1997; Walton, 2002). Ashton (1999) found that women turned to their children and friends more often, and men to their spouses, to receive support. One study reported a decrease in emotional support for both women and men over the
first 4 months after MI (Riegel & Gocka, 1995). Low emotional support has shown to be an independent risk for death in both women and men up to 6 months after an acute MI (Berkman et al., 1992).

Regarding appraisal support, women have reported a lack of affirmation and belief in their heart problems by caregivers and a need to communicate with other women in same situation about their problems (Benson et al., 1997; Helpard & Meagher-Stewart, 1998; LaCharity, 1999). Appraisal support has shown to be cardiac protective in women. This is often provided by workmates and friends, who offer help and good advice to recognize and cope properly with problems and difficulties (Orth-Gomér, 1998).

Hilding et al. (1997) described that the need for emotional, appraisal, and instrumental support was higher among women than men. Women’s social networks are often more demanding than supportive, which seems to differ from that of men, whose social networks often are supportive (Orth-Gomér, 1998). There are also some studies where no gender differences in social support were revealed (Conn et al., 1991; Rodeman et al., 1995; Steinke & Patterson-Midgley, 1996; Daly et al., 2000).

Secondary prevention programmes including support from professionals to reduce psychological distress have shown disparate findings with regard to impact on emotional distress. Cossette et al. (2001) found that short-term reductions in distress were related to lower levels of depression and anxiety symptoms 1 year after MI in both women and men. In another study where women had higher levels of depression symptoms compared with men, the intervention programme failed to improve depression in both women and men (Norrman et al., 2004). There are some indications that positive outcomes may be dependent on what type of support patients receive in light of the type of problems and what coping strategies they use (Cossette et al., 2002).

Following Schreurs and de Ridder (1997), social support is measured in the present thesis both as a coping strategy (one of the scales in JCS-60) and as a coping resource with a questionnaire developed in Sweden that includes subscales for social network and social support (Hanson et al., 1997). The questionnaire ‘is based on the view that the social environment is an important resource in coping with potential and established stressors in a person’s life’ (Östergren et al., 1991, p. 227). The development of the questionnaire was influenced by several authors, e.g. House, Cobb, Berkman, and Syme (Östergren, 1991). The questionnaire measures perceived available support (Sarason & Sarason, 1994)

**Quality of life**

Shepard and Franklin (2001) reviewed literature on cardiac rehabilitation and QoL. They found that most of the research has focused on the length
rather than the quality of the cardiac patient’s life and concluded that the current literature affirms the value of measuring QoL in patients with cardiac disease. According to Rose et al. (1996), MI survivors need to alter lifelong habits, change self-concepts, modify family relationships and perhaps work pattern. The road is filled with hazards that threaten physical and psychological well-being during recovery after a cardiac event (Moser, 1994).

QoL can be viewed as a multidimensional concept, which includes physical, psychological and social dimensions and well-being (Meeberg, 1993; Kinney et al., 1996; Bowling, 1998). According to Bowling (1998), the literature covers a range of areas of QoL such as functional ability including role functioning, the degree and quality of social interactions, psychological well-being, somatic sensation and life satisfaction. Kinney et al. (1996) describe four dimensions of QoL which can be important in connection with a chronic illness like MI, namely, symptoms and side effects of medication, physical functional status, social functioning and psychological status. In studies of QoL within nursing and medical fields, the more restricted concept of health-related quality of life (HRQoL) can be more appropriate to use (Nordenfelt, 1991), and is often used in the health care context (Ljunggren & Sjödén, 2003). A generic HRQoL measure should include at least the dimensions of physical, psychological and social functioning, as well as global perceptions of health and well-being (Anderson et al., 1993; Benzon et al., 1993). Additional important HRQoL dimensions are symptoms relevant to the disease and secondary effects of treatment (Benzon et al., 1993; Ljunggren & Sjödén, 2003). Thus, HRQoL is related to health and function, disease and treatment.

Both objective and subjective aspects of QoL can be measured (Nordenfelt, 1992; Meeberg, 1993; Fernández-Ballesteros, 1998). The objective aspect refers to external conditions of a person’s life (e.g. socio-economic factors or health and functional status) and the subjective aspects to a person’s internal perceptions of those conditions (Nordenfelt, 1992; Fernández-Ballesteros, 1998). There is a consensus that the emphasis should be on measuring subjective QoL (Benzon et al., 1993; Fernández-Ballesteros, 1998).

Quality of life in women and men after myocardial infarction

Lower levels in overall QoL and QoL dimensions such as health, functioning, socio-economic, psychological/spiritual, vitality and family have been reported by women from 1 week (Chan et al., 2005), 1 month (Bogg et al., 2000), 3 months (Bogg et al., 2000; Verrill et al., 2001), 5 months (Brink et al., 2002), and 6 months (Bogg et al., 2000) up to 1 (Wiklund et al., 1993; Deshotels et al., 1995: Loose & Fernhall, 1995) and 5 (Wiklund et al., 1989) years after cardiac events compared with men. In contrast, Daly et al. (2000)
did not find any gender differences in physical and psychological dimensions of QoL 1 month after MI. Some studies have reported improvements in QoL over the first year after MI for both women and men (Daly et al., 2000; Verrill et al., 2001; Brink et al., 2005; Chan et al., 2005), whereas another study did not find any improvements (Müller-Nordhorn et al., 2004).

In addition, studies have shown that more women than men experience health related problems after MI like chest pain (Wiklund et al., 1989, 1993; Deshotels et al., 1995), shortness of breath (Wilkund et al., 1993; Deshotels et al., 1995), lack of energy and sleep disturbances (Wiklund et al., 1989, 1993), and low physical functioning (Young & Kahana, 1993; Loose & Fernhall, 1995; Riegel & Gocka, 1995; Dixon et al., 2000). Some studies have found less emotional disturbances in women (Riegel & Gocka, 1995), and others, less emotional disturbances in men (Conn et al., 1991; Deshotels et al., 1995; Loose & Fernhall, 1995; Dixon et al., 2000; Bogg et al. 2000).

In the present thesis, the SF-36 Health Survey (SF-36) (Sullivan et al., 1994, 1997) was used for assessment of perceived HRQoL and the Quality of Life Index-Cardiac version (QLI) (Ferrans & Powers, 1985, 1992; Ferrans, 1990) for assessment of perceived QoL conceptualized as well-being.

Summary

Although coronary heart disease is manifested 10 to 20 years later in women than it is in men, women suffering from MI have physical, psychosocial and medical disadvantages compared with their male counterparts. These disadvantages may influence their perception of recovery after cardiac events. Women are often older when they experience an MI and, therefore, more likely to be widowed and lacking access to a spouse caregiver. This suggests that when integrating altered health requirements with their everyday lives, women and men may use different coping strategies to aid their recovery. This gives rise to questions of how women and men cope with MI, what support is available and what QoL they perceive. A literature review on coping with cardiac disease reveals that research findings relied on cross-sectional, rather than on longitudinal research designs (Livneh, 1999). More studies with longitudinal designs are needed with regard to 1) the limited research on coping, social support and QoL over time in women and men after MI and 2) MI being a chronic disease, which put demands on the person to cope with consequences of the disease in a life-long process. Results from longitudinal studies may help caregivers to emphasise relevant aspects when planning rehabilitation.
Aims

The overall aim of this thesis was to describe the life situation of women and men during their first year after MI with regard to health problems in daily life, how they coped with them, the social support available and the patients’ perceived QoL. An additional aim was to examine differences over time and between women and men in coping, social support and QoL. The specific aims were:

- To describe experiences of the daily life of Swedish women and men during the first months after an MI. The focus was on problems, managing problems and support from their networks (I).

- To describe experiences of the everyday life of Swedish women and men 4 to 6 months after an MI and their expectations for the future (II).

- To compare self-rated coping, social support, and QoL in Swedish women and men 1 month after an MI (III).

- To compare self-rated coping, social support and QoL in Swedish patients 1, 4 and 12 months after an MI with regard to (a) differences over time and (b) differences between women and men (IV).
Materials and methods

Design

In this thesis both a qualitative (I-II) as well as a quantitative (III-IV) approach was used. The combination of quantitative and qualitative methods increases the researcher’s possibility to give a more comprehensive picture. The two approaches provide different sources of knowledge that can have equal importance (Foss & Ellefsen, 2002).

A qualitative approach explores experiences of individuals in their everyday life and the researcher aims at understanding and interpreting the data with the context taken into consideration, to give a more extensive and comprehensive picture of the phenomenon. The investigator is the instrument and the skills and competence of this person are important for the trustworthiness of her/his findings. A quantitative approach gives a broad and general view of the topic under investigation and the aim is to explain and generalize the findings. This approach was used because it gave an opportunity to measure coping, social support and QoL in many MI patients and facilitated comparisons between women and men. Validity of the results depends on valid standardized instruments and standardized procedures. (Patton, 1990; Foss & Ellefsen, 2002).

Study I and II used a descriptive explorative design, study III, a cross-sectional two group comparative design, and study IV, a longitudinal two group comparative design. Figure 1 provides an overview of what period in the recovery after MI each separate study examines. Study I investigated the period from the onset through early recovery (retrospectively), study II the period 4 to 6 months after MI and expectations for the future, study III the early post discharge period 1 month after MI, and study IV changes over the first year. The time for each assessment of the longitudinal study was chosen for following reasons:

a) *Acute*: 1 month after an MI is a vulnerable time (Daly et al., 2000). The patients have only been at home for few weeks. They experience this period as acute.

b) *Short-term*: 4 months after an MI the patients are expected to have resumed work and finished the standard rehabilitation programmes.

c) *Long-term*: 12 months after an MI the patients have been in the third phase of rehabilitation for 9 months. This phase lasts for the rest of their lives (Day, 2003).
Study I

Study II

Study III

Study IV

Figure 1. MI = myocardial infarction; mo = month/s. An overview of what period in the recovery after an MI the separate studies investigated. Study I = from the onset through the first 4 to 6 months, retrospectively; Study II = at 4 to 6 months and further on; Study III = 1 month after MI; Study IV = 1, 4 and 12 months after MI.

Setting

The study took place in one hospital catchment area in the middle of Sweden. The routine follow-up of MI patients includes a visit to a cardiac rehabilitation nurse 2 weeks after discharge, where the patients obtain information about secondary prevention and are offered participation in a physical training programme for about 3 months and attendance at information sessions. A multidisciplinary team, including a cardiologist, a physiotherapist, a dietician, and a cardiac rehabilitation nurse communicate the information. Six weeks after discharge, the patients are offered a visit to a cardiologist.

Subjects

Study I and II

The informants, 20 women and 20 men, were selected from a consecutive series of 74 women and 97 men, who were participating in a larger longitudinal study and had experienced MI 4 to 6 months earlier. The purpose was to include both women and men of working age and older. One man declined participation later on. The mean age was 65 years (47-88 years) for women and 66 years (48-90 years) for men. Table 1 shows some characteristics of the interview group.
Table 1. Characteristics of the interview group.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Women (n = 20)</th>
<th>Men (n = 19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with a partner</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Work status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired / early retired</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Sick-listed / Unemployed</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Working</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Smoking</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>First MI</td>
<td>18</td>
<td>16</td>
</tr>
<tr>
<td>Heart event after MI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Re-infarction</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Revascularization</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Presenting symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Chest pain /sensation</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>No heart symptoms</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Cardiac rehabilitation programmes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attended</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Not been offered</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Declined</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

MI = myocardial infarction

Study III and IV

A consecutive series of patients was selected from the medical records in one hospital in the middle of Sweden between August 1999 and July 2001 for women and between August 1999 and August 2000 for men. Because of the lower incidence rate of MI in women (Flavell, 1994; Moore, 1995) a longer selection period was needed for them. The patients included met the following criteria: 1) they had entered the medical intensive care unit with a confirmed MI (according to ICD:10, I 10*) 1 month previously, 2) they lived within the hospital catchment area, 3) there were no communication barriers, and 4) they felt that they had enough physical and psychological capability to participate in the study. Power estimation, based on a power of 0.80 and p < 0.05 (Polit & Hungler, 1999), proposed that 63 women and 63 men should be included. The values (mean and SD) from the study by Deshotels et al. (1995), as reported for the total score of the Quality of Life Index-Cardiac version, were used for the estimation (women: m = 22.77, SD = 4.83; men:
m = 24.81, SD = 3.04). We decided to include 100 women and 100 men to create a satisfactory margin for dropouts.

Table 2 displays the target population, participants, deceased, and causes for exclusions and refusals at the three assessments. At the first assessment, 1 month after MI, 74 women and 97 men (48% and 54% of the eligible patients respectively) participated and at 12 months, 60 women and 88 men remained. Of the 23 dropouts, 4 women and 1 man died. The remaining patients declined further participation. The target population was older (m = 76.8, SD = 11.4) than the study group (m = 66.5, SD = 11.2; p < 0.001). No statistically significant difference in the age of women (67.0 years, SD = 11.5, 42-88) and men (66.2 years, SD = 11.0, 44-90) participating emerged in the study group.

Two thirds of the sample were married, educated at a basic level, and retired. When all of the patients (74 women and 97 men) of the study at 1 month were compared (III), more men (73%) than women (57%) were married or living together with a partner (p = 0.02). This difference disappeared at 4 months. In addition, more men (41%) than women (20%) had planned or implemented revascularizations during the first month after MI (p = 0.004). Men exercised more than women, on average at least 30 minutes 3.2 days per week for men and 2.2 days per week for women (p = 0.01). No statistically significant gender differences were found as regards educational level, work status, financial status, risk factors, previous heart events, stress level, medication, medical complications, and in hospital time. On average, the participants were hospitalized for 6.2 days (SD = 2.6).

When respondents who participated in all three assessments (60 women and 88 men, IV) were compared, no gender differences or differences over time emerged for the demographic characteristics, re-admissions, and cardiac rehabilitation variables, except for work status. More men worked at 12 months compared to at 1 month (21% vs. 8%, p = 0.01). Mean age of the women and men was 65.9 (SD = 11.1) and 65.7 (SD = 11.0), respectively. Fifty-seven per cent of the patients were offered cardiac rehabilitation, and 40% participated, mostly in exercise and diet-counselling programmes.
<table>
<thead>
<tr>
<th></th>
<th>Women n</th>
<th>Men n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Target population</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased before inclusion</td>
<td>68</td>
<td>54</td>
</tr>
<tr>
<td><strong>Exclusions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not entered the medical intensive care unit</td>
<td>41</td>
<td>22</td>
</tr>
<tr>
<td>Communication barriers(^1)</td>
<td>52</td>
<td>34</td>
</tr>
<tr>
<td>Severely ill(^2)</td>
<td>13</td>
<td>8</td>
</tr>
<tr>
<td>Did not live within the hospital catchment area</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Not included within two months after MI(^3)</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>117</td>
<td>85</td>
</tr>
<tr>
<td><strong>Eligible patients</strong></td>
<td>153</td>
<td>178</td>
</tr>
<tr>
<td><strong>Stated reasons for refusals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived that they lacked sufficient physical and psychological capability(^4)</td>
<td>42</td>
<td>32</td>
</tr>
<tr>
<td>Did not want to participate</td>
<td>37</td>
<td>46</td>
</tr>
<tr>
<td>Did not answer the questions within two months after MI</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>79</td>
<td>81</td>
</tr>
<tr>
<td><strong>Assessment time</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>74</td>
<td>97</td>
</tr>
<tr>
<td>4 months</td>
<td>65</td>
<td>89</td>
</tr>
<tr>
<td>12 months</td>
<td>60</td>
<td>88</td>
</tr>
<tr>
<td><strong>Reasons for ending participation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Died</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Increased own illness</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Increased spouse illness</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Declined further participation</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Did not answer (3 reminders)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>14</td>
<td>9</td>
</tr>
</tbody>
</table>

\(^1\) Did not understand Swedish, was demented, confused or did not understand the questions.
\(^2\) As judged by the cardiac nurse (often moribund)
\(^3\) Did not get in contact with the person or the person did not get the diagnosis in time.
\(^4\) Judgement by the patient her/him-self

Among women, more dropouts lived alone (p = 0.018), reported sleep disturbances (p = 0.002), depressed mood (p = 0.008), rated low social participation (p = 0.01), low social anchorage (to what degree the person belongs to formal and informal groups, p = 0.009), and lower overall QoL (p = 0.018) compared with those women who participated in all three assessments. In
addition, more women with three assessments reported available support from health care workers than the dropouts (p = 0.01).

Among men, more dropouts had diabetes (p = 0.048), rated low social participation (p = 0.008), low social anchorage (p = 0.04), lower QoL in physical functioning (p = 0.019), and used less self-reliant coping (p = 0.048) compared with men with three assessments.

Data collection

Study I and II
A semi-structured interview guide covered family, work, and rehabilitation (I-II). In addition, study I included problems related to their heart disease and treatment, managing these problems, and type of support they received or lacked from their social network. Study II included health problems, present worries and concerns and expectations for the immediate future.

Study III and IV
Data were collected by a study-specific questionnaire, a chart review protocol and four instruments. The instruments were selected because Swedish normative data were available (Sullivan et al., 1994; Cronqvist et al., 1997; Lindqvist et al., 2000) and because they have been used among patients with MI (Östergren et al., 1991; Scherck, 1992; Deshotels et al., 1995; Daly et al., 2000; Verrill et al., 2001; Müller-Nordhorn et al., 2004; Brink et al., 2005; Chan et al., 2005).

The study-specific questionnaire contained 38 questions, including demographic data (7 items), risk factors for MI (5 items), symptoms (8 items), side effects of medication (1 item), perceived efficiency in coping with physical, psychological, social and existential aspects of the heart disease (4 items), and from whom the participants received available support (13 items). One example of an item of ‘perceived efficiency in coping’ was: How well do you manage psychological reactions (e.g., worry, depressed mood and anger) related to your heart disease and treatment? The five response options were: very bad, bad, neither bad nor well, well and very well. Two items (financial status and exercise) used a 5-point scale (1 = the worst possible response option and 5 = the best possible response option). The remaining items had two response options: yes or no. The literature formed the basis for the questions about risk factors and symptoms (Martin & Lee, 1992; Young & Kahana, 1993; Riegel & Gocka, 1995; Ashton, 1999; Daly et al., 2000). The questionnaire was tested on two women (73 and 75 years old) and three men (50, 63, and 87 years old) with an acute MI. These patients were not included in the study. One question about re-admission was
added at 4 and 12 month assessments. Furthermore, four questions about cardiac rehabilitation were added at 4 months and one about other diseases, than heart disease at 12 months.

The chart review protocol contained 34 questions about medical data (diagnostic and therapeutic procedures, 17 items; risk factors for MI, 3 items; previous heart diseases, 3 items; medication, 5 items; medical complications, 3 items; time in intensive care unit, 1 item; hospital days, 1 item; and follow-up by a cardiac rehabilitation nurse, 1 item).

A description of the four instruments follows, and some instrument characteristics (scales, number of items and Cronbach alpha values) are shown in Table 3.
Table 3. Characteristics for the instruments.

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Scales (number of items)</th>
<th>Cronbach alpha earlier studies</th>
<th>Cronbach alpha present sample, 3 assessments</th>
<th>Scaling</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Jalowiec Coping Scale (JCS-60)</td>
<td>Total scale (60)</td>
<td>0.88 – 0.93*</td>
<td>0.94 – 0.96</td>
<td>4-grade scale</td>
</tr>
<tr>
<td></td>
<td>Confrontational (10)</td>
<td>0.78* – 0.88*</td>
<td>0.87 – 0.92</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evasive (13)</td>
<td>0.79* – 0.83*</td>
<td>0.82 – 0.87</td>
<td>0 = never used</td>
</tr>
<tr>
<td></td>
<td>Optimistic (9)</td>
<td>0.76* – 0.84*</td>
<td>0.80 – 0.87</td>
<td>3 = often used</td>
</tr>
<tr>
<td></td>
<td>Fatalistic (4)</td>
<td>0.58* – 0.60*</td>
<td>0.57 – 0.64</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotive (5)</td>
<td>0.62* – 0.65*</td>
<td>0.60 – 0.70</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Palliative (7)</td>
<td>0.51* – 0.62*</td>
<td>0.59 – 0.68</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Supportive (5)</td>
<td>0.56* – 0.65*</td>
<td>0.55 – 0.72</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-reliant (7)</td>
<td>0.54* – 0.75*</td>
<td>0.80 – 0.83</td>
<td></td>
</tr>
<tr>
<td>The social network and social support questionnaire</td>
<td>Total scale (22)</td>
<td></td>
<td></td>
<td>Vary from 2 to 7-grade scales</td>
</tr>
<tr>
<td></td>
<td>Social anchorage (5)</td>
<td>0.37*</td>
<td>Female</td>
<td>0.26 – 0.37</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.49*</td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social participation (13)</td>
<td>0.62*</td>
<td>0.62*</td>
<td>0.67 – 0.68</td>
</tr>
<tr>
<td></td>
<td>Emotional (3)</td>
<td>0.64*</td>
<td>0.61*</td>
<td>0.57 – 0.65</td>
</tr>
<tr>
<td></td>
<td>Instrumental (1)</td>
<td>-</td>
<td>-</td>
<td>4-grade (e.g. 1 = absolutely, 4 = not at all)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7-grade (0 = 0 persons, 6 = &gt;30 persons)</td>
</tr>
<tr>
<td>Instruments</td>
<td>Scales (number of items)</td>
<td>Cronbach alpha earlier studies</td>
<td>Cronbach alpha present sample, 3 assessments</td>
<td>Scaling</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>--------------------------</td>
<td>-------------------------------</td>
<td>---------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td><strong>The SF-36 Health Survey (SF-36)</strong></td>
<td></td>
<td></td>
<td></td>
<td>Vary from 2 to 6-grade scales</td>
</tr>
<tr>
<td>Total scale (36)</td>
<td>Physical Functioning = PF (10)</td>
<td>0.90 – 0.94</td>
<td>0.91*</td>
<td>0.88 – 0.91</td>
</tr>
<tr>
<td></td>
<td>Role-Physical = RP (4)</td>
<td>0.88 – 0.89</td>
<td>0.88*</td>
<td>0.67 – 0.86</td>
</tr>
<tr>
<td></td>
<td>Bodily Pain = BP (2)</td>
<td>0.82 – 0.88</td>
<td>0.93*</td>
<td>0.84 – 0.92</td>
</tr>
<tr>
<td></td>
<td>General Health = GH (5)</td>
<td>0.80 – 0.83</td>
<td>0.84*</td>
<td>0.74 – 0.79</td>
</tr>
<tr>
<td></td>
<td>Vitality = VT(4)</td>
<td>0.85 – 0.87</td>
<td>0.85*</td>
<td>0.78 – 0.83</td>
</tr>
<tr>
<td></td>
<td>Social Functioning = SF (2)</td>
<td>0.63 – 0.76</td>
<td>0.85*</td>
<td>0.65 – 0.72</td>
</tr>
<tr>
<td></td>
<td>Role-Emotional = RE (3)</td>
<td>0.80 – 0.81</td>
<td>0.79*</td>
<td>0.85 – 0.89</td>
</tr>
<tr>
<td></td>
<td>Mental Health = MH (5)</td>
<td>0.82 – 0.83</td>
<td>0.87*</td>
<td>0.85 – 0.86</td>
</tr>
<tr>
<td></td>
<td><strong>The Physical Component Score</strong> = PF+RP+BP+GH (21)</td>
<td></td>
<td></td>
<td>0.86 – 0.91</td>
</tr>
<tr>
<td></td>
<td><strong>The Mental Component Score</strong> = VT+SF+RE+MH (14)</td>
<td></td>
<td></td>
<td>0.88 – 0.90</td>
</tr>
<tr>
<td><strong>The Quality of Life Index – cardiac version (QLI)</strong></td>
<td>Total scale (36 + 36))</td>
<td>0.86 – 0.98</td>
<td>0.92 – 0.94</td>
<td>6-grade scales</td>
</tr>
<tr>
<td>Health and Functioning (16 + 16)</td>
<td>0.87 – 0.90</td>
<td>0.88 – 0.91</td>
<td>1 = very dissatisfied</td>
<td>6 = very satisfied</td>
</tr>
<tr>
<td>Socio-Economic (9 + 9)</td>
<td>0.73 – 0.89</td>
<td>0.75 – 0.78</td>
<td>1 = very dissatisfied</td>
<td>6 = very satisfied</td>
</tr>
<tr>
<td>Psychological/Spiritual (7 + 7)</td>
<td>0.88 – 0.90</td>
<td>0.85 – 0.86</td>
<td>6 = very important</td>
<td>6 = very important</td>
</tr>
<tr>
<td>Family (4 + 4)</td>
<td>0.63 – 0.79</td>
<td>0.58 – 0.69</td>
<td>6 = very important</td>
<td>6 = very important</td>
</tr>
</tbody>
</table>

*Swedish populations
The Jalowiec Coping Scale (JCS-60) measures use of coping strategies. Strong positive correlations ($r = 0.85 – 0.95$) between part A (use) and part B (effectiveness) for JCS-60 were demonstrated in a previous Swedish study of patients with end-stage renal disease (Lindqvist et al., 1998), which may indicate a risk that these two parts reflect similar or the same aspects of coping. Therefore, part B was not used in this study. The participants were asked to think about something stressful in connection with their heart disease and treatment and rate how often each strategy was used. Mean values were calculated for each subscale as well as for the total scale. Construct validity has been supported by factor analysis. Here follows a short description of each coping scale. Confrontational coping refers to problem solving strategies, Evasive, to avoiding, fleeing or repressing the problem, Optimistic, to positive thinking, Fatalistic, to feelings of pessimism and hopelessness, Emotive, to expressing and easing feelings, Palliative, to actions in order to feel well (e.g. eating or smoking more than usual), Supportive, to use of formal and informal support systems, and Self-reliant refers to depending more on oneself than on others to solve one’s problems. (Jalowiec, 1988, 1991; Cronqvist et al., 1997; Lindqvist et al., 2000).

The social network and social support questionnaire was developed in Sweden. The scores for each scale were dichotomised twice, first for each item on the scale, then for the distribution of the scale. The result of the calculation gives low network or support for 33% of the sample (highest tertile) and high network or support for 66% of the sample. A factor analysis indicates that the 2 scales of social network (social anchorage and social participation) measure different aspects of the psychosocial environment, but the 2 scales of social support (emotional and instrumental) may measure the same aspect of support. Social anchorage estimates to what degree the person belongs to formal and informal groups; Social participation assesses the person’s social activities during the past year. Emotional support estimates the social network’s ability to satisfy the person’s needs for sharing emotions and problems whereas Instrumental support measures the person’s access to practical aid and informational support (Östergren et al., 1991; Hanson et al., 1997).

The SF-36 Health Survey (SF-36) measures perceived HRQoL. The scores for each scale are coded, summarised, and transformed into a scale ranging from 0 (worst possible health) to 100 (best possible health). Construct validity has been supported by factor analysis and clinical group contrasts analysis. The SF-36 also provides a summary of several of the scales to 2 components supported by factor analysis. (Sullivan et al., 1994, 1997; Bowling, 1998; Persson et al., 1998; Ware & Gandek, 1998).

The Quality of Life Index – Cardiac version (QLI) measures perceived QoL conceptualised as well-being determined by how satisfied a person is with an aspect of life that is important to her or him. The QLI consists of two parts. Part 1 measures satisfaction with various aspects of life and part 2
measures the importance of those aspects to the subject. Scores are calculated by weighting each satisfaction response with its paired importance response. For a detailed description of this calculation, see paper III, p. 44. The adjustment produces the highest score for items that have high satisfaction/high importance responses and the lowest score for items that have high dissatisfaction/high importance responses. The range possible for the total scale and the subscales is 0 to 30, with a higher score indicating a higher QoL. Mean values were calculated for the subscales and the total scale. Construct validity has been studied by factor analysis and the contrasted groups method (Ferrans & Powers, 1985, 1992; Ferrans, 1990, 1997; Deshotels et al., 1995; Wingate, 1995).

There are two scales which cover a similar area but contain different questions - the Physical Functioning scale (the SF-36) and the Health and Functioning scale (the QLI, see Table 3). The Physical Functioning scale contains questions concerning to what degree the person can conduct different physical activities, whereas the Health and Functioning scale contains a broader range of questions (satisfaction with daily life with regard to symptoms, dependence, and the care they receive). On the SF-36 the person is asked to rate how life has been for them the last 4 weeks and on the QLI they rate how it is at present.

**Procedure**

**Study I and II**

An introductory letter was sent to the participants 4 to 6 months after their MI. The author phoned the informants and those interested in participating were asked to choose the place and time for the interview. The author conducted the interviews in the informants’ homes (n = 34), at outpatient clinics (n = 4) and at her place of work (n = 1) from January 2000 to November 2001. The interviewees signed a consent form. The interviewer opened the dialogue with the contextual issues (family, work, and rehabilitation) and then the participants were asked to tell about the problems they had experienced, how they had managed them and what kind of support/help they had received/lacked from lay and professional network members (I). In addition, they were asked to tell about how they experience daily life at present and how they conceive the immediate future (II).

They described their experiences in chronological order, from onset of symptoms, the hospital stay, from discharge to the time of the interview and further on. Clarifying questions were asked, such as: what do you mean?, how did you feel then?, and what did you think then?. The audiotape-recorded interviews, which lasted from 30 to 90 minutes, were transcribed verbatim.
Study III and IV

An introductory letter, a consent form, and questionnaires were mailed to the participants 1 month after MI. The same questionnaires were mailed 4 and 12 months after MI. After 1 week, the author phoned the patients at each assessment. Those interested in participating returned the signed consent form (at 1 month) and the completed questionnaires to the investigator within 1 to 2 weeks.

Ethical considerations

The regional Research Ethics Committee of Uppsala University approved the studies (I-IV; D no: 99085-40). The introductory letter contained information about the procedure and purpose of the study, and assurance that their answers were to be treated confidentially. In addition, the letter contained information that the participants would receive new requests to continue in the study 4 and 12 months after MI and that some of them also would be invited to an interview about 4 to 6 months after MI. Informed written consent was obtained from all patients at 1 month and once more at the interview.

Data analysis

Study I and II

The intention was to present the subjects’ experiences of everyday life after their MI. Therefore qualitative content analysis inspired by Graneheim and Lundman (2004) was chosen. The interviews of women and men were analysed separately in the following steps:

1. The author listened to the audiotapes and read and re-read the transcribed texts in order to become familiar with all of the texts.
2. The author divided the texts into three content areas (problems, managing, and social support) and analysed each separately (only for study I).
3. Meaning units (words, sentences or paragraphs) containing aspects related to each other through content and context were identified.
4. The meaning units were condensed (shortening the text while still preserving the core) and each condensed unit was abstracted and labelled with a code. The whole context was considered when condensing and coding.
5. The codes were compared based on differences and similarities and sorted into categories based on similarities.
6. The process of analysis involved back and forth movements between the whole text, the codes and the categories for each theme. The author then
formulated her interpretation of the underlying meaning of the categories into themes.

Study III
Descriptive statistics were used to examine the data. Differences between women and men were tested with the 2-tailed Student \( t \) test for continuous variables, and with the chi-square test for categorical variables. Fisher’s exact test was used when cells had an expected count less than 5. Two-factor analysis of variance (ANOVA) was used with marital status (lived alone or with a partner) and gender (woman or man) as independent variables. Reliability of the study instruments was expressed as Cronbach’s coefficient \( \alpha \). Missing values were substituted as recommended in the manual for the SF-36 (substitutes the respondent’s average score = a person-specific estimate; Sullivan et al., 1994) and the QLI (substitution of the mean; Ferrans, 1997). Substitution of the mean was used for the missing values for the JCS-60.

Study IV
Descriptive statistics were used to examine the data. The chi-square test was used for categorical variables and the 2-tailed Student \( t \) test for continuous variables when differences between women and men were tested. The McNemar test was used for categorical variables (Howell, 1997) and analysis of variance (ANOVA) for repeated measures for continuous variables (Tabachnick & Fidell, 1996) when differences over time were tested. Where significant time effects emerged for continuous variables, the sample was split between women and men. The 2-tailed Student \( t \) test was used as post hoc test to examine when group effects emerged. Adjustment for multiple comparisons using the Bonferroni test was made for time effects (Howell, 1997). In the other statistical analyses a p-value \( \leq 0.01 \) was considered statistically significant. Reliability of the study instruments was expressed as Cronbach’s coefficient \( \alpha \). Missing values were substituted as recommended in the manual for the SF-36 (Sullivan et al., 1994) and the QLI (Ferrans, 1997), respectively. For the SF-36 the respondent’s average score for the scale was used (a person-specific estimate) and for the QLI, substitution of the mean was used. Furthermore, substitution of the mean was used for the missing values for the JCS-60; there were 3 to 8 missing values. Only respondents who participated in all three assessments (60 women and 88 men) were included in the analyses.
Summaries of findings

Since several authors (Benzon et al., 1993; Kinney et al., 1996; Ljunggren & Sjödén, 2003) have argued that symptoms are important dimensions of HRQoL, the findings of measured symptoms (shortness of breath, tiredness, worry, sleep disturbances, depressed mood, chest pain, dizziness, and anxiety) have been reported in connection with results for SF-36 (HRQoL, III-IV).

Daily life shortly after myocardial infarction (I)

The aim was to describe experiences of daily life of Swedish women and men during the first months after an MI. The focus was on problems, managing problems and support from their network. The sample consisted of 20 women and 19 men.

Three themes were found: threatening ordinary life, struggling for control, and the ambiguous network. Each theme contains four categories.

Threatening ordinary life

The first category, changes in body and mind, describes pre-sensations the patients experienced some months before MI such as tiredness and indefinable uneasiness, symptoms at the onset and problems they had with physical symptoms, emotions, and cognition during the first months after their MI. The second category, uncertainty, contains descriptions of insecurity, fear of MI recurrence and death, and lack of knowledge about their heart disease. Difficulties in interpreting symptoms and who or what to trust were other concerns. These concerns restricted their activities in early recovery. The third category, lifestyle changes, refers to problems with lifestyle changes including a strong yearning for something, low motivation, lack of knowledge, and negative experiences with the lifestyle changes that they had made. The fourth category, restrictions, describes physical restrictions at hospital such as being in an overcrowded ward and the use of surveillance equipment that led to physical limitations, hygiene problems and sleep disturbances.
Struggling for control

*Negotiating with oneself* describes how women and men weighted the costs and benefits of making lifestyle changes and of accepting treatment. They sought explanations, they reasoned with themselves, and they tried to understand and motivate themselves. *Relying on one’s own capabilities* contains statements about how patients’ own knowledge, experiences, feelings, and intuition helped them to manage problems in everyday life after MI. *Changing attitudes and behaviour* describes how patients altered their lifestyle habits and became more sensitive to body sensations. They resisted demands from their network members and accepted physical and financial limitations. *Making one’s own decisions and acting for oneself* contains statements about what the patients did or did not do when they experienced symptoms and what physical and social activities they conducted. Patients also mentioned reasons for not participating in cardiac rehabilitation.

The ambiguous network

*Emotional support* describes from whom the patients received support to feel safe and encouraged. Women described large social networks, whereas men’s tended to be small and loosely knitted. *Specific knowledge* contains statements about from whom the patients received information and advice. The cardiac nurse was very much appreciated by both women and men. It was important that the information was repeated orally and written down. Exchanging experiences with other patients helped the participants to understand their own situation. *Practical assistance* describes what kind of practical assistance the patient received and from whom. Both women and men received a lot of practical help from their network members with most of the activities in daily living. The category *communication problems*, describes problems within areas of information, personal relations, and unspoken needs of the patients and with whom in their network they experienced these problems. Both women and men had problems in their communication with physicians as regards not receiving relevant information. The patients expressed that the caregivers were the least sensitive to their unspoken needs such as knowing whom to contact about health problems, having an earlier visit to a physician, and having a better composed rehabilitation group.

*To summarize,* physical symptoms and emotional distress were the most commonly described problems during the first months after an MI. The informants manage the problems by negotiating with themselves, relying on their own capabilities, changing attitudes and behaviour, and taking their own decisions. The network was generally supportive but rather often the informants also experienced communication problems when they interacted with their network. Experiences of women and men where the descriptions differed are provided in Table 5-6.
Present everyday life and expectations of the future (II)

The aim was to describe experiences of the everyday life of Swedish women and men 4 to 6 months after an MI and their expectations for the future. Twenty women and 19 men were interviewed.

Three themes were found: managing consequences of MI, managing changes in social life, and finding a meaning in what has happened.

Managing consequences of myocardial infarction

This theme contains five categories. The patients had to learn to live with changes in their health, lifestyle modifications, and emotional reactions; they had to find confidence in the future, and ask for support from their professional network.

*Health problems* contain descriptions of what symptoms the patients experienced. Fatigue, breathlessness, and chest pain were most frequently described. They experienced more symptoms than before their MI, but the symptoms had decreased in intensity over time or the patients handled them better. *Lifestyle modifications* refer to changes the patients tried to make concerning smoking, stress, diet, and physical activity. The lifestyle modifications could increase or decrease their well-being. *Emotional reactions* such as fear of death had diminished, but some of the patients experienced themselves as emotionally unstable. They related this to less energy for daily activities and worries of MI recurrence. *Confidence* contains statements about how to gain control in everyday life. Most of the patients felt that they had control in their daily life and could handle emotions, recognise their bodily sensations, and talk with others about their worries. But worries still limited some patients. *Professional network* describes what support the patients needed from caregivers and what kind of support they valued and from whom. Both women and men emphasised it was the nurses who stood for continuity, security, and practical help.

Managing changes in social life

This theme with three categories describes changes in work and social life, how the participants handled these changes and the support they received from their lay network.

*Work* contains statements about what the unemployed and sick-listed thought about work. Having a job was a confirmation of being healthy and back to normal life. The unemployed felt left outside society. The sick-listed most often expressed a wish to resume work, but wanted to begin part-time to avoid overstraining themselves. *Social activities* describes what social activities women and men valued and with whom. *Lay network* contains patients’ statements about experiencing great support from their lay network.
members. Some men tried to give the impression when they met friends that they were fitter than they actually were.

**Finding a meaning in what has happened**

The theme contains three categories and describes experiences of positive consequences, changes in life values, and hopes for the future that the patients expressed with regard to their MI.

*Positive consequences of MI* describes how the patients’ lives had changed in a positive way after their MI. Both women and men expressed getting a second chance. *Life values* contain statements of changes in life values. The patients paid more attention to and appreciated their social life with family and significant others and their own health. They valued their ability to do things and thought about things that were meaningful. Helping others and allowing themselves something special were important. *Hopes* for the future could be to live a healthy active life, to see grandchildren grow up, to get a job, and to expand their relations with others.

*To summarize,* many of the patients had not established a stable health condition, even if symptoms and emotional distress had diminished over time. They had to manage the consequences of their disease and changes in social life, find a meaning in what had happened, and confidence in the future. The support from their social network encouraged them to move on. Experiences of women and men where the descriptions differed are shown in Table 5-7.

**Gender differences 1 month after myocardial infarction (III)**

The aim was to compare self-rated coping, social support, and QoL in Swedish women and men 1 month after an MI. The sample consisted of 74 women and 97 men.

**Coping**

One month after MI women used more Evasive (p = 0.03) and Supportive (p = 0.003) coping than men. Compared with men, women rated psychological aspects of the heart disease, such as anxiety, worry, depressed mood and anger as more problematic to manage 1 month after MI (p = 0.04).
Social support

No statistically significant gender differences were found for the social network (Social anchorage and Social participation) or social support (Emotional and Instrumental support) scales 1 month after MI. More women perceived available support from friends ($p = 0.006$) and grandchildren ($p = 0.006$) and more men from their partner ($p = 0.002$). When only women (43%) and men (27%) who lived alone were compared at 1 month, the gender differences for available support from friends ($p = 0.03$) and partners ($p = 0.006$) remained. Most frequently rated support persons were family members and friends, followed by health care workers and neighbours.

Quality of life

The SF-36 showed that women rated lower HRQoL than men 1 month after MI both in the Physical ($p = 0.01$) and Mental ($p = 0.007$) component and in the Physical Functioning ($p = 0.049$), Role-Physical (measuring role limitations caused by physical problems; $p = 0.007$), Vitality ($p = 0.02$), and Mental Health ($p = 0.002$) scales. Interactions between marital status and gender were found in one component and three scales. Women who lived alone rated significantly lower in the Physical Component ($F_{3,167} = 4.9, p = 0.03$) and Role-Physical ($F_{3,167} = 5.9, p = 0.02$), Bodily Pain ($F_{3,167} = 5.3, p = 0.02$) and Social Functioning ($F_{3,167} = 5.7, p = 0.02$) scales compared with women who lived with a partner. The contrary emerged for men, namely, those who lived alone rated higher for the same component and scales compared with those who lived with a partner.

More women than men reported shortness of breath (60% vs. 38%, $p = 0.006$) and depressed mood (26% vs. 12%, $p = 0.03$) 1 month after MI.

The QLI showed, that women rated lower levels in overall QoL ($p = 0.04$) and in the Health and Functioning ($p = 0.049$) and Psychological/Spiritual ($p = 0.04$) scales 1 month after MI compared with men.

Differences over time and between women and men during the first year (IV)

The aim was to compare self-rated coping, social support and QoL in Swedish MI patients 1, 4 and 12 months after an MI with regard to (a) differences over time and (b) differences between women and men. Included in the analyses were those who participated in all three assessments - 60 women and 88 men. The overall significance values for differences over time and between women and men are reported in this section. See paper IV for p-values for a specific occasion between women and men or between two specific occasions.
Coping
The most frequently used coping strategies by both women and men were Optimistic, Self-reliant and Confrontational, which remained stable over the first year after MI. The use of Fatalistic coping decreased ($F_{2,292} = 5.6$, $p = 0.004$) for men between 1 and 4 months and remained at the lower level at 12 months. Women used more Evasive coping at 4 and 12 months ($F_{1,146} = 6.4$, $p = 0.01$) compared with men.

The mean values of perceived efficiency in coping with physical (e.g. chest pain, tiredness, and shortness of breath) and psychological (e.g. anxiety, worry, depressed mood, and anger) aspects of the heart disease were lower than for social (e.g. family and friends) and existential (e.g. life values and meaning of life) aspects among women and men at all three assessments. There was an increase in perceived efficiency in coping with physical aspects of the heart disease between 4 and 12 months ($F_{2,274}=4.5; p=0.01$) in the study group. There were no statistically significant differences between women and men for perceived coping with different aspects of the heart disease.

Social support
No statistically significant changes over time or between women and men were found for social network and support scales. One third (31-35%) of the sample rated low social participation over the first year. Low social anchorage was reported by 27-33% of the women and 22-28% of the men. Low emotional support was perceived by 20-28% of the women and 32-34% of the men, and low instrumental support by 17-28% of the women and 27-30% of the men.

No statistically significant changes over time for support persons available were found. The most frequently reported support persons available over time by both women and men were children (78-82%) followed by partners (72%) and friends (59-64%). More women than men perceived available support from grandchildren at 1 month ($p = 0.01$) and 12 months ($p = 0.002$), and from staff of their church at 1 month ($p = 0.01$).

Quality of life
HRQoL (the SF-36) increased over time for women for Physical Functioning, Role-Physical (measuring role limitations caused by physical problems), Vitality, Social Functioning, Role-Emotional (measuring role limitations caused by emotional problems), and Mental Health scales and for men for Physical Functioning, Role-Physical, Bodily Pain, Vitality, Social Functioning, and Role-Emotional scales ($F_{2,275-292} = 6.2 – 47.9, p = 0.000 - 0.003$). General health was the only scale stable over time. HRQoL increased for
Role-Physical scale for men between 1 and 4 months and a further increase was found between 4 and 12 months. An increase for Mental Health scale for women emerged between 4 and 12 months. For the remaining scales for women and men respectively, the increase emerged between 1 and 4 months, which remained at 12 months.

Main effects of groups were found for the Physical component scale and the Physical Functioning, Role-Physical, and Bodily Pain scales ($F_{1,145-146} = 4.3 – 7.1, p = 0.009 - 0.04$). When the $t$ test was used as a post hoc test, no gender differences emerged for the SF-36.

Table 4 displays symptoms for women and men who participated at all three assessments. The two most frequently reported symptoms for both women and men on all three occasions were shortness of breath and tiredness. More men experienced dizziness at 12 months compared with at 4 months ($p = 0.01$). More women than men reported shortness of breath at 1 month ($p = 0.005$) and dizziness at 4 months ($p = 0.002$). Women also reported more symptoms than men at 4 months (women: mean = 2.5; men: mean = 1.8; $p = 0.01$).

<table>
<thead>
<tr>
<th>Table 4. Changes in symptoms for women and men over the first year after MI (McNemar test was used for comparisons over time).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
</tr>
<tr>
<td>Tiredness</td>
</tr>
<tr>
<td>Worry</td>
</tr>
<tr>
<td>Chest pain</td>
</tr>
<tr>
<td>Depressed mood</td>
</tr>
<tr>
<td>Sleep disturbances</td>
</tr>
<tr>
<td>Dizziness</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
</tbody>
</table>

QoL (the QLI) decreased for the sample for the socio-economic scale between 1 and 4 months which remained at 12 months ($F_{2,292} = 4.3, p = 0.02$). The test failed to reveal significance for the socio-economic scale when the study group was divided into women and men. No statistically significant differences between women and men were found for the QLI.

Table 5-7 displays patterns of experiences of women and men over the first year in a chronological order, both those patterns in the interviews where the descriptions between women and men differed (I-II) as well as summaries of gender differences (III-IV).
<table>
<thead>
<tr>
<th>Subject</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Coping</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Study I</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom descriptions at onset</td>
<td>Described atypical MI symptoms.</td>
<td>Described typical MI symptoms.</td>
</tr>
<tr>
<td>Own actions at the onset</td>
<td>Often problems interpreting their symptoms.</td>
<td>Often no problems interpreting their symptoms.</td>
</tr>
<tr>
<td></td>
<td>Minimized or repressed them. Practiced self-treatment and tended to delay seeking treatment.</td>
<td>Asked for help from their network and tended to seek treatment more promptly.</td>
</tr>
<tr>
<td>Provoking factors for chest pain</td>
<td>Mostly emotions.</td>
<td>Mostly physical efforts.</td>
</tr>
<tr>
<td>Accepting their MI</td>
<td>Mostly no problems accepting.</td>
<td>Some problems accepting.</td>
</tr>
<tr>
<td>Lifestyle modifications</td>
<td>Problems with lifestyle changes related to family habits and lack of knowledge of how to practice recommendations.</td>
<td>Problems with lifestyle changes related to low motivation and a strong yearning for tobacco.</td>
</tr>
<tr>
<td>Relying on one’s own ability</td>
<td>Relied on others’ support to acquire knowledge and manage everyday life.</td>
<td>Relied on their own ability to acquire knowledge and manage everyday life.</td>
</tr>
<tr>
<td><strong>Study II</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional reactions</td>
<td>Felt angry, because they had repressed their own needs for many years.</td>
<td>Felt neglected and worthless with reference to physical weakness and unemployment.</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>Described many lifestyle changes within four areas (smoking, stress, diet, and physical activity).</td>
<td>Described some lifestyle changes within three areas (smoking, stress, and diet) and some went on as before their MI.</td>
</tr>
<tr>
<td>Subject</td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td>---------</td>
<td>-------</td>
<td>-----</td>
</tr>
<tr>
<td><strong>Coping</strong>&lt;br&gt;Study II continues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hopes</td>
<td>To be able to travel again, not have to move from their house, undergo revascularization, and get ‘a quick death’.</td>
<td>To be able to do physical activities as they did prior to their MI.</td>
</tr>
<tr>
<td><strong>Study III</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping at 1 month</td>
<td>Women used more evasive and supportive strategies than men. Psychological aspects of the heart disease (anxiety, worry, depressed mood, anger) were more problematic to manage for women than for men.</td>
<td></td>
</tr>
<tr>
<td><strong>Study IV</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping at 4 months</td>
<td>Women used more evasive strategies than men.</td>
<td></td>
</tr>
<tr>
<td>Coping at 12 months and over time</td>
<td>Women used more evasive strategies than men. The use of fatalistic coping decreased over time for men.</td>
<td></td>
</tr>
</tbody>
</table>

MI = myocardial infarction
Table 6. Patterns of experiences of women and men over the first year after MI (social support, I - IV).

<table>
<thead>
<tr>
<th>Subject</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Study I</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication problems with caregivers</td>
<td>Difficult to have a dialogue with the physician and receive relevant information from the dieticians.</td>
<td>Divergent opinions between men and physicians and lack of continuity with the physician.</td>
</tr>
<tr>
<td>Reasons for not participating in cardiac rehabilitation programmes</td>
<td>Practical due to time, place, and no car.</td>
<td>Practical due to no parking place and personal due to group activities, did not want to recall their MI, and it interfered with their work.</td>
</tr>
<tr>
<td>The network</td>
<td>Large, often supportive, but sometimes also demanding and overprotective.</td>
<td>Smaller, loosely knitted and supportive, but some men had great relational problems with their partner.</td>
</tr>
<tr>
<td><em>Study II</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional network</td>
<td>Valued the interaction with the rehabilitation team and the participants.</td>
<td>Valued the individual contacts with the cardiologists.</td>
</tr>
<tr>
<td>Work</td>
<td>Felt support from workmates and work managers, and they promised themselves to decrease work stress.</td>
<td>Felt lack of support from authorities in searching for a job.</td>
</tr>
<tr>
<td>Social activities</td>
<td>Emphasised social activities with family, relatives, and friends.</td>
<td>Emphasised social activities and wanted to be in demand for and of use to society.</td>
</tr>
<tr>
<td>Lay network</td>
<td>Great support from their network.</td>
<td>Great support for most of them. Some of them did not have any support from their family.</td>
</tr>
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</table>
Table 6 continues

<table>
<thead>
<tr>
<th>Subject</th>
<th>Women</th>
<th>Men</th>
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<tr>
<td><strong>Social Support</strong></td>
<td></td>
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<tr>
<td><em>Study III</em></td>
<td></td>
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</tr>
<tr>
<td>Social support at 1 month</td>
<td>More women perceived support being available from grandchildren and friends, and more men from their partners.</td>
<td></td>
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<tr>
<td><em>Study IV</em></td>
<td></td>
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<tr>
<td>Social support at 1 months</td>
<td>More women than men perceived support being available from grandchildren and staff of their church.</td>
<td></td>
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<tr>
<td>Social support at 12 months</td>
<td>More women than men perceived support being available from grandchildren.</td>
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MI = myocardial infarction
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<thead>
<tr>
<th>Subject</th>
<th>Women</th>
<th>Men</th>
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<tbody>
<tr>
<td><strong>Quality of life</strong></td>
<td><strong>Study II</strong></td>
<td></td>
</tr>
<tr>
<td>Health</td>
<td>Great improvements after revascularizations which remained.</td>
<td>Deteriorated over the months for some.</td>
</tr>
<tr>
<td>Lifestyle modifications</td>
<td>Increased physical activity improved their well-being.</td>
<td>Longing for tobacco decreased their well-being.</td>
</tr>
<tr>
<td>Positive consequences of MI</td>
<td>They prioritized themselves, released themselves from ‘necessities’, experienced better financial status, and were more go-ahead.</td>
<td>They saw opportunities to do things they had missed, friends had returned, they had learnt to talk about feelings, and death did not scare them.</td>
</tr>
<tr>
<td><strong>Study III</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms at 1 month</td>
<td>More women than men reported shortness of breath and depressed mood.</td>
<td></td>
</tr>
<tr>
<td>Quality of life at 1 month</td>
<td>Women rated lower HRQoL (the SF-36) than men in the Physical and Mental component and in the Physical Functioning, Role-Physical, Vitality, and Mental Health scales. Women rated lower overall QoL (the QLI) and in the Health and Functioning, and Psychological/ Spiritual scales compared with men.</td>
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<tr>
<td><strong>Study IV</strong></td>
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<tr>
<td>Symptoms at 1 month</td>
<td>More women than men reported shortness of breath</td>
<td></td>
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<tr>
<td>Symptoms at 4 months</td>
<td>More women than men reported dizziness, and women experienced on average more symptoms compared with men.</td>
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<tr>
<td>Symptoms over time</td>
<td>More men reported dizziness at 12 months compared with at 4 months.</td>
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<tr>
<td>Quality of life over time</td>
<td>HRQoL increased over time for women in the Mental Health scale and for men in the Bodily Pain scale.</td>
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</table>

MI = myocardial infarction, HRQoL = health-related quality of life, QoL = quality of life
Discussion

The overall aim of this thesis was to describe the life situation of women and men during their first year after MI with regard to problems in daily life, how they coped with them, the social support available and the patients’ perceived QoL. An additional aim was to examine differences over time and between women and men in coping, social support and QoL.

A general pattern found in the interviews (I) was that the patients strived for balance in daily life. On the one hand they had problems emanating from a life-threatening condition and ingrained habits, their own uncertainty and inability to handle the situation, lack of knowledge, and communication problems with their network. On the other hand, they had resources such as self-confidence, successful strategies and support from their social network. In early recovery they were balanced between a wish for independence and normality and a wish for security. Most of them accepted their MI and the limitations they experienced, a pattern also described in other studies (Sutherland & Jensen, 2000; Tobin, 2000; Bergman & Berterö, 2001, 2003).

Six months after their MI, many of the patients did not experience a stable health condition, even if symptoms and emotional distress had decreased over time. They continued to handle the consequences of their heart disease and changes in social life. The meaning they found in what had happened and the support they experienced from their social network encouraged most of them to move on to a redefined normal life or to find a better way of living, but some of them experienced predominantly negative consequences of their illness (II).

Summaries of statistically significant differences in studies III and IV are provided in Table 5-7.

As a whole, there were more similarities than differences between women and men. This may indicate that other variables than gender or interactions between gender and other variables might have a stronger impact on coping, social support, HRQoL and QoL. Important variables may be age, marital status, socio-economic status, co-morbidity and ethnicity.

The discussion of the findings is mostly based on the content in Tables 5-7 and begins with coping (Table 5) followed by social support (Table 6) and QoL (Table 7). The findings will also be discussed with regard to The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) and hope (Dufault & Martocchio, 1985).
Coping with daily life after myocardial infarction

The patients experienced tiredness and indefinable uneasiness some months before their MI. Similar findings are reported by McSweeney and colleagues (2003).

Women used metaphors when describing their chest pain sensations at the onset of MI and their descriptions differed from those of men. Some studies have found that both women and men use metaphors when describing their MI symptoms (Jairath, 1999; Gassner et al., 2002), whereas other studies show that men often use distinct and concrete descriptions of their symptoms when they communicate with caregivers (Vodopiutz et al., 2002; Foss & Hofoss, 2004). Many studies have reported gender differences in symptom descriptions of MI (Lundberg, 2000; Albarran et al., 2002; Ćulić et al., 2002; Kristofferzon et al., 2003; Patel et al., 2004; Chen et al., 2005). Explanations of the differences could be that women and men communicate in a different way or they have different experiences of pain (Swahn, 1998).

Many women had problems interpreting their symptoms at onset, repressed or minimized them, and practiced self-treatment because they did not want to bother others. These findings are in accordance with other studies (Kristofferzon et al., 2003; Banks & Malone, 2005; Lockyer, 2005). As a result of the strategies women use at the onset, they may delay in seeking medical treatment and, thereby, miss access to morbidity and mortality-reducing therapies (Ashton, 1999; Grace et al., 2003). The delays were often increased because women more often consulted a health centre before going to the emergency department at the hospital, which also was found in another study (Holliday et al., 2000). Few men repressed or misinterpreted their heart symptoms, which contrasts with findings by White and Johnson (2000), where the majority of men misinterpreted their symptoms.

Men relied on their own ability to acquire information and manage everyday life, whilst women relied on caregivers’ ability to have full control over their disease and were dependent on family members’ willingness to change habits for succeeding with their lifestyle modifications. This is sustained by other findings, where women presented themselves in acquiescent way, leaving all decisions to the experts (Vodopiutz et al., 2002). Men relied more on their own initiatives to acquire knowledge. This is consistent with other studies reporting that men have great need for information, and they obtain it from many resources (Zuzelo, 2002; Kristofferzon et al., 2003; White, 2003). Some men had difficulties accepting their MI and sought information to support their point of view. They felt neglected and worthless with respect to physical weakness. Other studies have also found that men do not want to accept that their pain is of cardiac origin and they are concerned about physical weakness after MI (White & Johnson, 2000; Kristofferzon et al., 2003). As described by Charmaz (1995) these men struggled against their illness not with it. They view their illness as the enemy and did not want to
accept more restricted lives and went on as before their MI. This attitude may increase the risk for recurrence. Other studies have shown that men in general may have problems accepting loss of physical power to perform social roles due to feelings of disempowerment and thereby do not want to perceive themselves as ill (Miers, 2002). Women who had undergone revascularizations expressed that they were healthy now, but knew they could get a recurrence. According to Brink (2003) they accepted their MI as a chronic condition. Women also accepted their MI and learnt to handle the limitations caused by the disease; thus, they struggled with the illness not against it (Charmaz, 1995), findings which are sustained by Brink (2003).

Women used more evasive and supportive coping strategies than men, which correspond with some earlier studies (Martin & Lee, 1992; Bogg et al., 2000; Lindqvist et al., 2000), but not with findings by Daly et al. (2000). Evasive coping was, for example, used by women at the onset, when they avoided bothering others with their problems and practiced self-treatment, which may increase the delay time and this in turn may have a negative impact on cardiac prognosis. Frasure-Smith et al. (2002) found that a psychosocial intervention programme (the Montreal Heart Attack Readjustment Trial) for post-MI patients had a significantly worse impact on survival in both women and men who used repressive coping strategies. Patients who were visited by nurses received some information about cardiac disease and risk factors, which may have been a source of distress for patients who preferred repressive or avoidance coping strategies. But women also used evasive coping when they slowed down and avoided stressful situations, which gave positive consequences in well-being. Women had also more problems than men handling emotional distress such as anxiety and worries related to their heart disease 1 month after MI, which may have encouraged them to use the supportive network to a higher degree than men. Women were angry with themselves for repressing their own needs for many years. This anger encouraged them to be less subservient and more self-assertive. They gave less priority to household duties and thought more of their own needs, which is congruent with other studies (Doiron-Maillet & Meagher-Stewart, 2003; Kristofferzon et al., 2003). The scores in fatalistic coping decreased for MI men to the same level as for men in a sample of the Swedish population (Lindqvist et al., 2000). MI men may have experienced a defeat in physical functioning and felt powerless in their early recovery and therefore used more fatalistic coping at that time.

Optimistic, self-reliant, and confrontational coping were the most commonly used strategies among patients in this study and the strategies were stable over time. The pattern of coping strategies used is comparable with findings in other studies (Scherck, 1992; Cronqvist et al., 1997; Lindqvist & Sjödén, 1998; Daly et al., 2000; Lindqvist et al., 2000) and may reflect aspects of Western lifestyle, with a strong tendency to regard problem-focused coping as more successful than emotion-focused coping (Lazarus, 1993).
Some authors (Coyne & Gottlieb, 1996; de Ridder & Schreurs, 2001) suggest that this stability may reflect a habitual way of coping, which patients with a chronic disease may develop over time. Livneh (1999) found some support in his literature review on coping with cardiac disease for problem-focused and optimistic coping strategies increasing psychosocial adaptation to cardiac disease, which is congruent with other research findings (Holahan et al., 1996; Bennett & Connell, 1999). Avoidance and emotion-focused coping may be adaptive strategies helpful during the acute phase of MI, whereas problem-focused coping may be more beneficial to a long-term perspective that involves coping with lifestyle changes, limitations and compliance with medical treatment (Leventhal & de Ridder, 1996).

Support from the social network

The physician-related communication problems described by women in this study such as difficulties with the dialogue and problems receiving relevant information have also been found in other studies (Benson et al., 1997; Helpard & Meagher-Stewart, 1998; Marcuccio et al., 2003). Men did not always have trust in physicians and they received irrelevant information. Foss and Hofoss (2004) found that the complaints most often mentioned by men were mistakes in diagnosis and treatment. The MI patients expressed worries of MI recurrence; one reason for these worries may have been their experience of lack of information or irrelevant information about their health status, physical functioning, and cardiac rehabilitation, which resulted in feelings of uncertainty about their future. These findings are supported by earlier research (Jaarsma et al., 1995; Tobin, 2000; Roebuck et al., 2001; Bergman & Berterö, 2003; Doiron-Maillet & Meagher-Stewart, 2003; Svedlund & Danielson, 2004; From Attebring et al., 2005; Hanssen et al., 2005).

Hanssen et al. (2005) reported that patients express problems using the standardised information often given at discharge after an MI, and questions often emerge when they are at home. In the present study both women and men saw the nurses as those who kept continuity and could answer the questions that cropped up at home. In addition they infused security into the patients, helped them to contact other professionals, and gave them practical support.

Women valued the interactions with the rehabilitation team and the fellow patients, which is also shown by other studies (Bergman & Berterö, 2003; Doiron-Maillet & Meagher-Stewart, 2003; Kristofferzon et al., 2003; Hanssen et al., 2005; Perry & Rosenfeld, 2005). This support and the support from patients’ lay network were very important for recovery and the support encouraged women to conduct and maintain lifestyle changes. Men valued the individual contacts with the cardiologists, and physician’s authority has shown to be of importance for how men view their possibilities for the future.
(Kristofferzon et al., 2003; White, 2003). These findings are congruent with those reported by Cossette et al. (2002), who found that listening and being encouraged to talk about worries related to symptoms were linked to better post-MI outcomes in women, whereas receiving advice e.g. about recovery and diet improved outcomes in men.

Women mentioned that the time or place did not suit them or the fact that they did not drive a car as reasons for not participating in cardiac rehabilitation. Even other studies report similar findings (Lieberman et al., 1998; Davidson et al., 2003; Day, 2003; Dollard et al., 2004; Pâquet et al., 2005). Men mentioned personal reasons such as not liking group activities, not wishing to recall their MI or the rehabilitation intervening with their work. The only reason found in the literature of those mentioned was that work interfered with cardiac rehabilitation (Pâquet et al., 2005). When the patients who participated in structured cardiac rehabilitation were compared with those who did not, some statistically significant differences in variables were found. Those who did not participate were older, had fewer supportive persons available, and rated lower HRQoL in the physical dimension. More patients in the group who participated in rehabilitation experienced support from grandchildren, siblings, parents, friends, neighbours, workmates, and from health care workers. They also participated in more social activities. Studies have reported that worse physical functioning and older age may have a negative impact on the participation rates in cardiac rehabilitation (Lieberman et al., 1998; Cottin et al., 2004; Day, 2004; Husak et al., 2004; Johnson et al., 2004).

Some men experienced relational difficulties with their partners, which caused them problems in their recovery. Partner’s support has shown to predict readjustment in men recovering from an MI (Ben-Sira & Eliezer, 1990). Women felt less strain from their work than before their MI and the work-mates and work managers supported them. Some unemployed men were distressed due to lack of support from authorities in searching for a job.

The interviewed women described large and often supportive lay networks. This was supported by results from the studies using a quantitative approach (III-IV). But sometimes they also found their network demanding and overprotective. Most of the interviewed men described very supportive networks, and those who had relational problems with their partner or lived alone had supportive friends or neighbours available. These findings are supported by earlier research (Orth-Gomér, 1998).

Quality of life

More women than men experienced heart-related problems such as shortness of breath, depressed mood, and dizziness the first 4 months after MI, which is comparable with earlier research findings (Conn et al., 1991; Wiklund et
Compared with men, women also rated lower levels of HRQoL (the SF-36) and QoL (the QLI) in physical and psychological dimensions (Table 3 shows the scales) 1 month after MI. The findings are supported by prior research (Wiklund et al., 1989, 1993; Deshotels et al., 1995; Loose & Fernhall, 1995; Bogg et al., 2000; Dixon et al., 2000). Several of the studies which found gender differences in QoL, also reported gender differences in demographic variables (e.g. age and marital status). The gender differences in the present study disappeared in the physical dimension for the QLI and in the psychological dimension for the SF-36 and the QLI when dropouts were excluded at 1 month. When a higher level of statistical significance was used ($p \leq 0.01$) to avoid type 1 error (Howell, 1997), then also the gender differences in the physical dimension for the SF-36 disappeared. No gender differences were found at 4 and 12 months. One explanation for the pattern found may be that the female dropouts differed in several variables compared with females who participated in all three assessments. More dropouts lived alone, had health problems, rated low social support, and lower overall QoL. Thus, most of the gender differences found in the SF-36 and the QLI may have been related to female dropouts. Norris et al. (2004) found that women reported significantly lower HRQoL than men one year after cardiac catheterization after adjustment for demographic, clinical, co-morbid and treatment variables. They concluded that further studies need to examine gender differences in HRQoL after adjustment for psychosocial variables such as social support and depression, because adjustment for traditional medical variables fails to explain differences between women and men with coronary heart disease.

Improvements in HRQoL were evident in women and men in seven of the scales in the SF-36 over a 12-month period, but the pattern for women and men was slightly different. No improvement was shown in the QLI (see scales in Table 3). Previous research shows disparate findings. Daly et al. (2000) reported an increase in one of the scales in the SF-36 (Role-Emotional) over a 1 month period, Chan et al. (2005) found improvements in all eight scales over a 6-month period for the whole study group (69% men), and Brink et al. (2005) described improvements between 5 and 12 months in women mainly in scales included in the Mental component, whereas men demonstrated an increase in most of the scales included in the Physical component (see scales in Table 3). These findings are congruent with the present study to some extent, where an increase was shown in the Mental Health scale in women and in the Bodily Pain scale in men and a further increase for the Role-Physical scale in men. One study did not find any improvements in HRQoL (the SF-36) over a 12 month period in MI patients (Müller-Nordhorn et al., 2004; 80% men). In a study by Verrill et al. (2001) both
women and men showed improvements in subscales and total scale scores in the QLI between entry and discharge in a 12 week early out-patient cardiac rehabilitation programme. Two of the studies reported that women were significantly older than men (Daly et al., 2000; Brink et al., 2005).

Improvement was found in HRQoL over time for women in the Mental Health scale. One explanation may be the female dropouts, but other explanations may also exist. In the interviews women described great improvements after revascularizations and said that lifestyle modifications increased their well-being. In addition, they recognized several positive consequences with respect to their MI. Women also perceived that they manage physical problems related to their heart disease more efficiently over time. Taken together, these things may have decreased their emotional distress and increased their psychological well-being. This explanation is supported by a previous study, where the emotional distress in women improved to comparable level with men after revascularization (Mitchell et al., 2005).

There were patients who experienced that their life situation had changed for the better. They gave examples of a second chance, changes in personal life priorities, healthy lifestyle changes, improved close relationships, and greater appreciation of health and life. Some other studies have reported similar findings and the authors argue that it is important to discover possible positive experiences of MI, not solely negative consequences. To focus on positive experiences can be a great resource in recovery (Laerum et al., 1987; Petrie et al., 1999).

In comparison with age-matched and gender-matched scores for Swedish normative data (Sullivan et al., 1994, 1997) women and men in this study rated statistically significant lower levels of HRQoL (the SF-36) 1 month after MI. The differences between the study group and the normative group remained for most of the scales at 12 months. This may indicate that the cardiac event is dramatic both for women and men and it may influence HRQoL for a long time period (Bennett & Connell, 1999). Al-Windi and co-authors (1999) studied well-being in a Swedish community. They found that married women and men rated higher social and mental well-being but lower physical well-being compared with others. This is in accordance with the MI men in the present study regarding physical well-being but contrasts with regard to social well-being. For the MI women the results showed the contrary by supporting the previous findings regarding social well-being but not regarding physical well-being. Al-Windi et al. (1999) did not discuss these findings and stated that their study was explorative.

**Living with a chronic illness**

Most interviewees seemed to think of their MI as a chronic condition (except some men). The Shifting Perspectives Model of Chronic Illness is a model
for understanding the experience of adults who have a chronic physical illness and contains both illness and wellness perspectives (Paterson, 2001). The perspectives overlap, but either illness or wellness is in the foreground at a specific time. The model describes living with chronic illness as an ongoing, continually shifting process. The underlying assumption is that the perception of reality, not the reality itself is the basis for a person’s response to chronic illness. The person is conscious about the shifts between the perspectives. Persons with their illness in the foreground focus on sickness, suffering, loss and burden related with their illness. They tend to be self-absorbed and not sensitive to the needs of others. The MI patients recognized the illness perspective when they were struck by MI. Worries concerned personal health, life and death. For many the MI was unexpected and they had not enough time to adapt and felt overwhelmed by the changes in body and mind. Focusing on illness is a way of conserving energy and learning to manage the disease and its consequences. The patients focused on gaining knowledge of their heart disease and how to handle the consequences and lifestyle changes relating to MI to prevent recurrences. Women assumed the illness perspective to receive attention from their family in order to change food habits and physical activities. Other factors found to shift perspective from wellness to illness are signs of disease progression, dependence, and hopelessness because they threaten the patients’ own control over their situation. These signs were also found among MI patients (e.g. deteriorated health, felt neglected and worthless due to physical weakness, avoided physical activities and to be alone).

Renewed hope and optimism help to shift to a wellness perspective (Paterson, 2001). Persons with wellness in the foreground focus on self as a person not as a diseased body. They revise what is possible and normal and emphasise emotional, spiritual, and social aspects of life. Outcomes of this perspective can be a renewed appreciation of life and significant others, and more attention to the needs of others. The MI patients expressed optimism, humour and hope. They did not want to get stuck into their disease and restrictions and tried to think about something other than their disease. Furthermore, they looked forward to getting a job, described their health as good, redefined ‘normal’ life, appreciated life, family and significant others and paid more attention to these aspects.

Descriptions of hope were found in the interviews. According to Dufault and Martocchio (1985) particular hope, in contrast to general hope, is linked to an object of hope. The MI patients linked their hope to specific objects. Hope could perhaps be seen as an inward coping resource with regard to the authors’ statements that particular hope ‘provides an incentive for constructive coping with obstacles’ (Dufault & Martocchio, 1985, p. 381). Hope is goal-oriented and contains six dimensions. Examples of these dimensions were found in the interviews. Feeling positive, trustful and optimistic about the outcomes are related to the affective dimension. MI patients hoped to get
a job and stated that they were optimistic. Wishing, thinking, learning and judging contribute to the cognitive dimension. Patients thought about things that gave them meaning in their life. The behavioural dimension contains psychological, physical, social and religious actions. Patients conducted lifestyle modifications and thereby hoped to prevent recurrence. The affiliative dimension describes relationships with both living and dead; patients expressed a hope to live long enough to see their grand children grow up. The temporal dimension focuses on experience of time (past, present, and future). Patients hoped to become fit enough to undergo revascularization. The contextual dimension focuses on a life situation that is a part of persons’ hope. Hope is often experienced in situations (context) of loss, where the persons readjust goals and values. MI patients revised life values and their perceptions of the meaning of life (Dufault & Martocchio, 1985). Hope seems to be a strong resource to infuse into patients with chronic illness and it contributes to a shift from illness to a wellness perspective. But it is important to know that both illness and wellness perspectives have their good and bad points; for example, to ignore symptoms and needed lifestyle changes to sustain the wellness in the foreground can contribute to disease progression (Paterson, 2001).

Methodological considerations

Design and research perspectives

A qualitative and a quantitative approach were combined in this thesis to give a more comprehensive picture of the phenomenon investigated. Each approach has its strengths and weaknesses.

The qualitative methods gave an opportunity to gain insight into how the patients experienced and thought about their everyday lives after MI. This can not be observed, it must be narrated (Patton, 1990). One weakness may be the retrospective design in study I. The informants might have forgotten what they really felt some months ago, but that they have had time to reflect and dissociate themselves from the acute phase could also be a strength. What they remember may be of utmost importance.

The quantitative methods gave an overview of what coping strategies women and men used over time, what support they found available and how HRQoL and QoL changed. The longitudinal approach was used because MI often is a sign of an underlying chronic disease, the consequences of which persons have to cope with in a life-long process. Previous research (Livneh, 1999) has also indicated the need of longitudinal research designs on coping with cardiac disease.

Knowledge gained from the two perspectives is complementary and the findings in study I and II (qualitative approach) point in the same direction.
as findings in study III and IV (quantitative approach). For example, most of the informants learnt to manage everyday life after their MI and they even discovered some positive changes, which they related to their MI. This pattern is congruent with the findings of increased HRQoL over time.

Data collection

Interviews
The interviews were carefully planned. The informants chose the place and time and the interview opened with contextual issues to make it easier for the informants to feel comfortable with the environment and the dialogue. The author, who has more than five years experience of cardiac nursing, conducted all the interviews (M-LK). My pre-understanding of the context was thought to be useful when gathering and analysing data. During recent years I have been a lecturer in nursing, so I was not involved in the care of the participants. The interview guide was used as a basic checklist to make sure that all relevant topics were covered. Probing questions were used to check that I did not misunderstand what the informants told me and when there was a need for clarification.

Measures
All of the instruments included in the thesis have been tested for validity and reliability and used among MI patients, two of them also in Swedish MI samples (the SF-36 and the social network and social support questionnaire). Furthermore, two of the instruments have normative data available for the general Swedish population (the SF-36 and the JCS-60).

There is no standard (common sense) for what an acceptable Cronbach $\alpha$ coefficient should be, but a value over 0.70 is probably sufficient in making group-level comparisons (Polit & Hungler, 1999). The social network and social support questionnaire showed low Cronbach $\alpha$ values (Table 3) probably because of few items in two of the scales and reduced variance as the result of a dichotomized answer format in one of the scales (social anchorage). The questionnaire may also have problems with low sensitivity because of reduced variance depending on how the scales are estimated (dichotomized twice). These limitations may have diminished the probability of detecting differences within and between genders. Even four scales in the JCS-60 did not have acceptable reliability (Table 3). Low alpha values for the same scales have also been found in other Swedish studies (Cronqvist et al., 1997; Lindqvist et al., 2000).

The reliability for the SF-36 and the QLI was satisfactory. The improvement in HRQoL found for the SF-36 was not supported by the QLI. One reason can be a lower sensitivity to detecting changes over time in the QLI compared with the SF-36, because of the difference in scale range (Table 3).
Data analyses

Content analysis
The interviews were intended to provide data about the patients’ experiences of their MI and everyday life during their recovery. The qualitative content analysis seemed to be suitable when the purpose was to interpret the underlying meaning of the subjects’ experiences in a specific context (Graneheim & Lundman, 2004). This differs from, for example, phenomenological analysis, where the purpose is to find the ‘essence’ of the experience of a phenomenon (Creswell, 1997).

Statistical significance
In study IV a great number of statistical tests were performed on the same data. To avoid the risk of mass significance (type I error), the Bonferroni correction and a higher statistical significance level (p-value < 0.01) were used. This may have increased the risk of type 2 error, failing to detect differences when they really exist (Howell, 1997).

According to statistics textbooks (Tabachnick & Fidell, 1996; Howell, 1997), the scales in the instruments used in the thesis are data on an ordinal level and nonparametric tests should be used. Because many nursing and medical research journals with referees accept parametric tests on ordinal data and the normative data also are based on parametric tests, they were also used in this thesis. When nonparametric and parametric tests on the same data were compared the results of the tests did not differ.

Schofield et al. (2000) argue that we need to be cautious about giving too much weight to statistically significant gender differences. It is unlikely that findings indicating no gender differences will ever get published, but when gender differences are found they most often do not encompass all men and all women.

Trustworthiness

Interview data
Validity and reliability are not appropriate concepts to use when discussing trustworthiness of studies with an explorative design and a qualitative data analysis (I-II). Instead the methodological considerations can be discussed through four other concepts: credibility, dependability, transferability, and conformability (Guba & Lincoln, 1983; Sandelowski, 1986; Woods & Catanzaro, 1988).

Credibility refers to how well the constructed themes of underlying meaning reflect the informants experiences of the studied area. The credibility in the present study was established by a large amount of data, representative quotations from the transcribed text, informant validations (during the interview), and discussions with supervisors and fellow researchers leading to a
broad agreement on the logic of the categorisations and the constructed themes. The researcher’s pre-understanding of the context may support his or her credibility in the process of gathering and analysing data, but it can also be a weakness if the researcher takes patients’ statements for granted and neglects to probe important statements. Weaknesses may be that three informants had their partner nearby during the interview (withholding sensitive data) and the retrospective design in study I.

**Dependability** concerns how well the research process and the analysis can be followed. This was established by open dialogue with the author’s supervisors and fellow researchers throughout the research process to minimize inconsistencies and achieve a logical and clear documentation. Table 2 in study II is one example of how the author has tried to give the reader a picture of the process of analysis.

**Transferability** describes to what extent the findings are transferable to other illness situations and other parts of the health care system. This was facilitated by a thorough description of the research process and the demographic characteristics of women and men in the study group. In addition, the Shifting Perspectives Model of Chronic Illness gives some support for that the findings may be transferable to patients with other chronic diseases (Paterson, 2001). Variations in demographic characteristics of the study group and inclusion of both women and men may strengthen the transferability of the findings. But social and cultural factors - and not merely gender alone - may have an impact on how informants experience and manage their everyday life after an MI (Schofield et al., 2000; Galdas et al., 2005).

**Confirmability** is said to be supported if the findings are credible, dependable, and transferable (Sandelowski, 1986).

**Validity**
A strength in study III and IV should be the rather equal numbers of women (43%) and men (57%) in the sample. Differences between dropouts and the subjects who participated in all three assessments may have some impact on the validity of the findings in study IV. The use of Bonferroni correction and a higher statistical significance level may also have an impact on validity because of the risk of type 2 error (Howell, 1997). Therefore, the findings should be interpreted with caution.

**Generalisability**
Reasons that may limit generalization to the population from which the sample was selected are that the participants were not randomly selected and the patients in the population were older and more severely ill than the patients in the sample (Table 2). In addition, no difference in age was found between women and men in the study group. This is incongruent with the fact that MI is manifested 10 - 20 years later in women than in men (Flavell, 1994, Moore, 1995, Graves & Miller, 2003), thus, the women in the sample are
expected to be older than the men. Another weakness is that the sample was
selected from only one hospital area.
Conclusions

The description of the life situation of women and men after myocardial infarction was obtained from both a qualitative and a quantitative approach showing that:

- Women and men strived for balance between problems and resources in daily life after a myocardial infarction. How well they succeed depends on how secure they feel, how well they communicate their needs to their network and how sensitive their network is to their spoken and unspoken needs (I).
- The patients moved on in three different ways. Many wished to go back to a redefined normal life; they accepted their shortcomings in everyday life and mostly managed them quite well. Others found a better way of living. The MI had opened their eyes so they saw possibilities of making new priorities. Some experienced predominantly negative consequences of their MI such as deteriorated health, difficulties with handling symptoms, necessary lifestyle modifications, modifications in working conditions, and lack of social support (II).
- The first month after myocardial infarction seems to be a vulnerable period, perhaps especially for women, who used more evasive and supportive coping strategies and experienced a lower quality of life compared with men (III).
- Patients had not established a stable health condition 6 months after myocardial infarction, even if symptoms and emotional distress had diminished over the months (II).
- Coping and social support for both women and men were stable over time and the most frequently used coping strategies were optimistic, self-reliant and confrontational (III-IV).
- The health-related quality of life improved in the study group during the first 4 months and remained at that level during the first year (IV).
- Both women and men perceived that they managed physical problems related to heart disease better over time (IV).
- More women than men perceived support from grandchildren and the staff of their church, and they used more evasive coping strategies than men (III-IV).
Clinical implications

Some suggestions for clinical practice and rehabilitation based on findings from the present studies (I-IV) are the following:

- Social networks and patients themselves must be made aware that women’s and men’s cardiac symptom descriptions differ.
- Patients should be encouraged to seek treatment promptly and be informed of the consequences a delay can cause.
- Patients’ coping strategies should be taken into account when planning interventions.
- It can be valuable to develop clinical measures to assess coping and coping resources (internal and external) to guide information and education for patients.
- Caregivers should assess who is and is not supportive in the patient’s social network.
- Information and recommendations should be individualized and relevant to the patient’s specific situation.
- More emphasis should be put on how to cope with limitations, symptoms, and emotional distress.
- Community-based cardiac rehabilitation programmes can be developed as a complement to hospital-based programmes to support patients for longer periods (up to 12 months or more). These programmes can give the patients the continuity of support they often lack.
- To focus on patients’ hopes and positive experiences of their illness can be a great resource in cardiac rehabilitation.
- Women and men should be encouraged to describe their objections to attending rehabilitation programmes in order to better facilitate their participation.
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Sammanfattning (Summary in Swedish)

Syfte: Det övergripande syftet med avhandlingen var att beskriva livs situationen hos kvinnor och män under första året efter en hjärtinfarkt (MI). Aspekter som studerats är upplevda problem i vardagen, hantering (coping) av dessa, tillgängligt socialt stöd och upplevd livskvalitet (QoL). Även skillnader över tid och mellan kvinnor och män angående coping, socialt stöd och QoL har undersömts.

Metod: Ett konsekutivt urval av 74 kvinnor och 97 män gjordes 1 månad efter MI och patienterna följdes över året. I delstudie I och II med kvalitativ ansats, intervjuades 20 kvinnor och 19 män ur studiegruppen. Delstudie I var retrospektiv och hade fokus på hantering av problem och stöd patienterna upplevde sig ha från sitt sociala nätverk från insjuknandet och under första månaderna efter MI. Delstudie II undersökte upplevelser i vardagen 4 till 6 månader efter MI och förväntningar inför framtiden. Delstudie III och IV hade en kvantitativ ansats, där kvinnors och mäns skattningar av coping, socialt stöd och QoL jämfördes både 1 månad efter MI (delstudie III; 74 kvinnor och 97 män) och över tid (delstudie IV; 1, 4 och 12 månader efter MI; 60 kvinnor och 88 män).


Nyckelord: hjärtinfarkt, kvinnor och män, könsskillnader, problem, coping, socialt stöd, livskvalitet


Nordenfelt, L. (1992) Livskvalitet – vad är det, går det att mäta? (Quality of life – what is it, is it possible to measure?). Socialmedicinsk tidsskrift, 1, 3-7.


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