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# When time matters

Patients' and spouses' experiences of suspected  
acute myocardial infarction in the pre-hospital phase

Ingela Johansson



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Linköping 2006

**When time matters: Patients' and spouses' experiences of suspected acute myocardial infarction in the pre-hospital phase**

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*Människan är inte som ett pussel – de nyfunna bitarna kompletterar inte bilden,  
de skapar bara nya frågor.*

Sven Delblanc



*To Mum, the guardian angel on my shoulder*



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# ABSTRACT

The overall aim of this thesis was to describe patients' and spouses' experiences of suspected acute myocardial infarction in the pre-hospital phase. A descriptive survey study was conducted to identify various factors influencing patient delay in 381 patients with suspected myocardial infarction hospitalised at a Coronary Care Unit (I) and ambulance utilisation among 110 myocardial infarction patients (II). In order to obtain a deeper understanding of the myocardial infarction patients' own conceptions about the event, an interview study with a phenomenographic approach was conducted with 15 strategically selected myocardial infarction patients (III), within 72 hours after admission to hospital. Finally, the pre-hospital experiences of 15 spouses of myocardial infarction patients were also studied through interviews with a phenomenographic approach, within 48 hours after the affected partner's admittance to hospital (IV). The results showed that 59% of the patients with suspected acute myocardial infarction delayed > 1 hour after onset of symptoms. The most common reasons given for delay in seeking hospital admittance were: (1) Did not consider the symptoms as to be severe enough that they warranted hospital care, (2) thought the symptoms to be temporary and that they would disappear, (3) the chest pain was more of a dull pain, (4) or, as one third of the patients chose to do, contacted the general practitioner instead of going directly to the hospital (I). Furthermore, as a first action, 59% consulted their spouse for advice about what to do henceforth. The most common reason for additional delay when the decision to go to hospital had already been taken was that the myocardial infarction patients stated that they were unaware of the advantages of a rapid decision-making process. Sixty percent went by ambulance, but it was the spouse (40%) or the personnel at the general practitioner's office (32%) who called the emergency service number, rather than the patient him/her self (5%). The most frequently given reasons for not choosing ambulance, were that the patients did not perceive their symptoms as being serious enough to require ambulance transportation (43%), followed by that they had not thought about ambulance as an alternative at all (38%). As a third reason for not going by ambulance, the patients stated that it was unnecessary to call an ambulance when being affected by symptoms related to a myocardial infarction (26%). The patients who called an ambulance differed in some respects from those who went by private alternatives; patients with large infarctions (ST-Elevation Myocardial Infarction) went by ambulance more frequently, as did patients suffering from nausea and severe chest pain (II). The patients expressed in the interviews how the interaction with others, described as the need for supportive environment, worries for the family and the

utilisation of the health-care resources, was of great importance in the pre-hospital phase. Likewise, symptom awareness, with earlier experiences of a similar situation to compare with, denying the seriousness of the situation and the use of different self-care strategies, were important in order to manage the situation. Vulnerability, expressed as anxiety and a lack of control, also influenced the decision-making process in the pre-hospital phase (III). Spouses seemed to have a strong influence on the course of events when their partner suffered an acute myocardial infarction and it emerged from the interviews how the spouses in many cases were influenced into sharing the denial of the affected partner by respecting his/her independence. The spouses accepted the partner's need for control; took earlier marital roles and experiences into account; restraining own emotions and seeking agreement with their partners, contributing to delay. However, being resourceful by sharing the experience; having knowledge; understanding the severity; being rational and consulting others when needed, seemed to have a positive influence on the decision time in the pre-hospital phase (IV).

**Conclusion:** The reasons for delaying or not in the pre-hospital phase, as well as the reasons for utilising the ambulance services or not, varied considerably between individuals. Earlier experiences of MI did not influence what actions to take; instead patients' feelings, emotional attitudes to MI symptoms, inadequate coping strategies, and spouses' influences were important components in the pre-hospital phase.

**Keywords:** ischaemic heart disease, acute coronary syndrome, acute myocardial infarction, pre-hospital phase, symptom interpretation, decision-making, spouses, patient delay, ambulance utilisation

## SAMMANFATTNING

Det övergripande syftet med detta avhandlingsarbete var att beskriva patienters och makars erfarenheter av den prehospitala fasen i samband med insjuknande i en misstänkt hjärtinfarkt. En deskriptiv enkätstudie genomfördes på 381 hjärtintensivpatienter med misstänkt hjärtinfarkt för att identifiera olika faktorer som påverkar patientfördröjning (I), samt för att beskriva ambulansnyttjande hos 110 patienter med diagnostiserad hjärtinfarkt (II). I syfte att nå en fördjupad förståelse av hjärtinfarktpatienternas egna uppfattningar om insjuknandet, genomfördes en intervjustudie med en fenomenografisk ansats på 15 strategiskt utvalda patienter, inom 72 timmar efter ankomst till sjukhus (III). Slutligen så studerades även den prehospitala erfarenheten hos 15 makar, inom 48 timmar efter det att partnern drabbats av hjärtinfarkt, genom en fenomenografisk ansats (IV). Resultatet visade att 59% av patienterna med misstänkt hjärtinfarkt dröjde > 1 timme efter insjuknandet med beslutet att uppsöka sjukhusvård. De vanligaste förklaringarna till att avvakta var: (1) Ansåg inte att symptomen var så pass allvarliga att de krävde sjukhusvård, (2) trodde att symptomen var temporära och skulle försvinna, (3) bröstsmärtan var av en mer molande karaktär, (4) eller, som en tredjedel av patienterna gjorde, kontaktade sin vårdcentral istället för att åka direkt till sjukhuset (I). Vidare så konsulterade 59% av patienterna sin make/maka som en första åtgärd för att diskutera vad man skulle göra. Den vanligaste orsaken för ytterligare fördröjning när beslutet väl var taget att åka till sjukhus, angav hjärtinfarktpatienterna berodde på att de inte kände till fördelarna med en snabb beslutsprocess i händelse av en hjärtinfarkt. Sextio procent ringde efter ambulans, men det var makarna (40%) eller personalen på vårdcentralen (32%) som ringde larmnumret, och inte patienterna själva (5%). De vanligaste orsakerna för att inte välja ambulans, var att patienterna inte uppfattade sina symptom som så pass allvarliga att de krävde ambulans (43%), följt av att de inte hade tänkt på ambulans som en möjlighet överhuvud taget (38%). En tredje orsak för att inte välja ambulans, var att patienterna ansåg att det var onödigt att ringa efter ambulans när man drabbats av hjärtinfarktliknande symptom (26%). De patienter som ringde efter ambulans skiljde sig åt i några avseenden jämfört med dem som valde privata transportalternativ; de med stora hjärtinfarkter (s.k. ST-höjningsinfarkt) åkte ambulans signifikant oftare, liksom de patienter som upplevde illamående och/eller svår bröstsmärta (II). Patienterna uttryckte i intervjuerna hur interaktionen med andra, beskriven som ett behov av en stödjande omgivning, oro för familjen och nyttjandet av hälso- och sjukvårdens resurser, var viktiga i den prehospitala fasen. Likaså var medvetenhet om symptomen, med tidigare erfarenheter att jämföra med,

förnekelse av allvarlighetsgraden i situationen och användandet av olika egenvårdsstrategier, viktiga för att kunna hantera situationen. Sårbarhet, uttryckt som ångest och brist på kontroll påverkade också hjärtinfarktpatienternas beslutsprocess före uppsökande av sjukhusvård (III). Makarna verkade ha en stark påverkan på händelseförloppet när en partner insjuknade i hjärtinfarkt, och i intervjuerna framkom det tydligt att många makar delade sin drabbade partners förnekelse genom att respektera dennes vilja till oberoende i situationen. Makarna accepterade partners behov av kontroll; beaktade tidigare erfarenheter av rollfördelning i äktenskapet; undanhöll sina egna känslor och sökte överenskommelse med sin partner, bidragande till fördröjning i den prehospitla fasen. Men när makarna var handlingskraftiga genom att de delade erfarenheten med den drabbade partnern; hade tidigare kunskap; förstod allvaret i situationen; var rationell och kontaktade andra för råd vid behov, verkade detta ha en positiv påverkan på beslutstiden (IV).

**Konklusion:** Orsakerna till fördröjning eller inte i den prehospitla fasen, liksom nyttjandet av ambulans eller inte, varierade till stor del mellan individer. Att ha tidigare erfarenhet av hjärtinfarkt påskyndade inte förloppet; istället så var patienternas känslor och attityder till symptomen, inadekvata coping strategier, liksom makarnas inflytande viktiga delar innan uppsökande av sjukhus.

**Nyckelord:** ischemisk hjärtsjukdom, akuta koronara syndrom, akut hjärtinfarkt, prehospital fas, symptomtolkning, beslutsfattande, maka/make, patientfördröjning, ambulansnyttjande

## LIST OF ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

- I            Johansson I, Strömberg A, Swahn E. Factors related to delay times in patients with suspected acute myocardial infarction. *Heart Lung* 2004;33:291-300
  
- II           Johansson I, Strömberg A, Swahn E. Ambulance use in patients with acute myocardial infarction. *Journal of Cardiovascular Nursing* 2004;19:5-12
  
- III          Johansson I, Swahn E, Strömberg A. Patients' conceptions of suffering an acute myocardial infarction. *European Journal of Cardiovascular Nursing* Submitted 2006
  
- IV          Johansson I, Swahn E, Strömberg A. Spouses' conceptions of their partners suffering an acute myocardial infarction: A qualitative analysis. *Manuscript* 2006

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## ABBREVIATIONS

ACC	American College of Cardiology
ACS	Acute Coronary Syndrome
ED	Emergency department
CABG	Coronary Artery Bypass Graft Surgery
CAD	Coronary Artery Disease
CCU	Coronary Care Unit
CHD	Coronary Heart Disease
ECG	Electrocardiogram
EMT	Emergency Medical Transportation
ESC	European Society of Cardiology
GP	General Practitioner
IHD	Ischaemic Heart Disease
MI	Myocardial Infarction
NSTEMI	Non ST-Elevation Myocardial Infarction
NSTE-ACS	Non ST-Elevation Acute Coronary Syndrome
PCI	Percutaneous Coronary Intervention
STEMI	ST-Elevation Myocardial Infarction
STE-ACS	ST-Elevation Acute Coronary Syndrome
VAS	Visual Analogue Scale



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## INTRODUCTION

During the most recent decades, the treatment of myocardial infarction patients has changed dramatically. Time has become an important issue as delay from symptom onset until reperfusion has great impact on myocardial damage and thus on prognosis regarding death and heart failure. As patient delay has been shown to be the most difficult part to change it has become increasingly important to understand the patients' pre-hospital behaviour. Understanding of the complexity of underlying thoughts, symptom interpretation and coping mechanisms that influence the patient's way of reasoning when experiencing a myocardial infarction, is essential in order to minimise the patient's decision time. However, it is obvious that not only the patients' conceptions influence which actions taken but also the near relatives'. Thus it has become necessary to integrate also the spouse in the care taking process and to study the patient-spouse interaction and final decision-making. Only in such a context it will be possible to modify the myocardial infarction patient's pre-hospital behaviour and reduce the delay time to appropriate treatment.



## **BACKGROUND**

### **Ischaemic heart disease**

Ischaemic heart disease (IHD) is usually caused by obstructive atherosclerosis of one or more of the coronary arteries. The acute manifestation of IHD is gathered under the term acute coronary syndromes (ACS). A further sub-division is into ST-elevation ASC and non-ST-elevation ACS, which has practical implications, since the acute treatment is quite different due to the underlying pathogenesis<sup>1-3</sup>.

### **Epidemiology**

The prevalence of cardiovascular diseases is about 12% in Sweden today. In the age group > 65 years almost 50% are affected by cardiovascular diseases with 10-14% being hospitalised every year, usually due to IHD<sup>4,5</sup>. Both incidence and mortality due to acute MI have decreased since the 1980s in most of the western countries<sup>4,6</sup>. However, acute MI remains the major cause of death in men over 45 and in women over 65 throughout Europe<sup>6</sup>, representing 12% and 6%, respectively, of all deaths<sup>7</sup>. Data from Sweden show that more patients die outside hospital in the acute phase of an MI than during the first 28 days after the event<sup>4</sup>. In 2002, approximately 34 000 persons were hospitalised due to acute MI in Sweden, women representing 35-40%, with the incidence of MI being slightly over 600 per 100 000 inhabitants the same year<sup>8</sup>.

### **Pathogenesis of acute coronary syndrome**

The myocardium's demands for oxygen and nutrients are continuously met by the blood flowing through the coronary arteries. If this blood flow is markedly reduced or interrupted, ischaemia with accumulation of waste products and cell membrane disintegration results in ischaemic chest pain<sup>3</sup>. The cause of non ST-elevation MI (NSTEMI) is usually the rupture of an atherosclerotic plaque, leading to thrombus formation and partial occlusion of the coronary artery involved, leaving some coronary flow<sup>9</sup>. When the myocardium is injured, it releases biochemical markers, which can be detected by their elevation in the peripheral blood. The electrocardiogram (ECG) is seldom normal and even at an early stage ST-segment shift and T-wave changes are the most reliable electrocardiographic indicators of NSTEMI<sup>10</sup>. ST-elevation MI (STEMI) occurs when an abrupt and complete occlusion of the involved coronary artery leads to acute ischaemia and necrosis,

inducing changes in electrical potentials resulting in ST-elevation development detected on an ECG <sup>11,12</sup>. As a consequence of ischaemia, necrosis occurs first in the sub-endocardial myocardium, beginning as early as 15 to 20 minutes after coronary artery occlusion. During longer periods of occlusion, a wave front of necrosis moves from the sub-endocardial zone to involve progressively more of the transmural thickness of the myocardium <sup>9</sup>.

Figure 1 shows a schematic view of the progress of heart muscle damage (modified from Karz <sup>13</sup>).

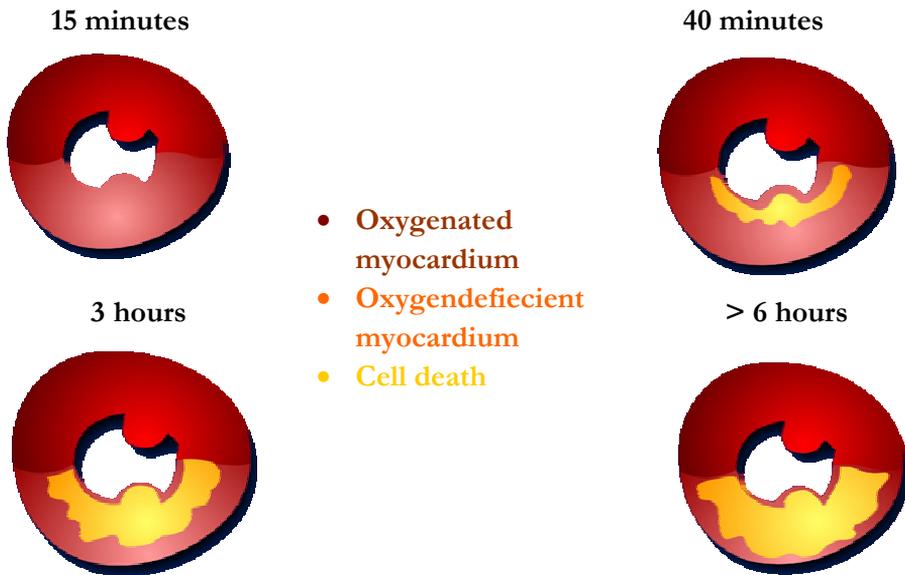


Figure 1. Progress of heart muscle damage

## Symptoms in ischaemic heart disease

### Chest pain

Chest pain is one of the most frequently reported symptoms in general population surveys. Both physical and psychological factors have been suggested as causes of chest pain <sup>14</sup>, which is, second only to abdominal pain, the most common reason for emergency department (ED) visits <sup>15</sup>. The differential diagnosis of life-threatening conditions other than acute ischaemia presenting as chest pain is well known: Pulmonary embolism, aortic dissection, oesophageal rupture, pericarditis, spontaneous pneumothorax, pneumonia, and certain acute abdominal conditions

(cholecystitis, pancreatitis and perforated ulcer)<sup>16</sup>. Approximately 35-40% of patients presenting to the ED with chest pain ultimately receive a cardiac diagnosis of some kind<sup>17</sup>, while the prevalence of an acute MI ranges from only 4% to 15%<sup>18-20</sup>. Among chest pain patients, those belonging to older age groups have an increased risk of acute MI, while women presenting with chest pain have a lower risk of MI than men do<sup>21,22</sup>.

Precordial or retrosternal chest pain remains the initial main symptom in 80-90% of acute MI in both men and women<sup>23-27</sup>. However, studies have found the presence of chest pain in patients with acute MI to be as low as 67%<sup>28-33</sup>, and in women 57%<sup>34</sup>. The pain may wax and wane, but usually lasts > 20 minutes. The classical symptoms of an MI typically include chest discomfort, and the character of the pain may be described as pressure, squeezing, crushing, burning, or aching with radiation to the arms, the back, neck, jaw, or stomach<sup>23-27</sup>.

### **Other symptoms**

Other symptoms than chest pain may occur in those experiencing an acute MI and these are: Weakness and fatigue<sup>27,35</sup>, shortness of breath and nausea<sup>24,25,28,36</sup>, cold sweat, dizziness or syncope<sup>16,37</sup>. Historically, these symptoms have been considered to be atypical and associated with the prodromal period as opposed to the acute event<sup>35</sup>. However, many MI patients experience less typical symptoms and there is evidence that absence of chest pain is more common in women, the elderly, those diagnosed as having diabetes, hypertension, heart failure, and stroke<sup>27,30,34,38</sup>. Instead, women have been found to experience more dizziness, unusual fatigue, and upper back pain than men do<sup>36,39</sup>. Older people have reported symptoms that are milder and more ambiguous compared with their younger counterparts<sup>40</sup>, and those aged 75 or older are most likely to present without chest discomfort<sup>30</sup>. Patients with diabetes are instead more likely to experience weakness, shortness of breath, and nausea compared to those without diabetes<sup>41</sup>.

### **Importance of early treatment in acute myocardial infarction patients**

The primary goal of acute medical treatment in patients with acute MI is to relieve symptoms, minimise the myocardial damage and prevent life threatening coronary events. The aim of long term treatment is to prevent re-occlusion in the coronary arteries, prevent ischaemia, prevent arrhythmia and progression of stenosis<sup>7,10,12</sup>.

## Acute medical treatment

Medical treatments to be considered as important alternatives in the early phase of an MI are anti-ischaemic agents, aiming at decreasing myocardial oxygen need or inducing vasodilatation. These include  $\beta$ -blockers and nitrates<sup>7, 10, 12</sup>. Nitrates relieve pain, but has not been shown to reduce future coronary events<sup>42, 43</sup>, while  $\beta$ -blockers contribute to a 20-30% relative reduction in mortality and re-infarction in patients with MI<sup>44, 45</sup>. Additionally, antiplatelet therapy decreases the risk of thrombus formation and thereby decreases mortality by 10-15% in patients with MI<sup>46</sup>, and GPIIb/IIIa-inhibitors have been shown to have a beneficial effect on top of that of the traditional treatment in ACS patients<sup>7</sup>. Early administration of GPIIb/IIIa-inhibitors also seems to improve epicardial patency (TIMI flow) before percutaneous coronary intervention (PCI) and results in a better myocardial tissue perfusion/ST-resolution after the procedure<sup>47, 48</sup>.

### *Reperfusion therapy*

At the end of the 1980s, the lifesaving effects of fibrinolytic therapy in STEMI patients, were proven<sup>49-51</sup>. Since the STEMI usually results from the occlusion of a coronary artery, increasing evidence suggests that the morbidity and mortality relate directly to the duration of ischaemia<sup>52-60</sup>. Benefits from fibrinolytic therapy diminish on a minute-to-minute basis<sup>58</sup>, with the therapy achieving the greatest effect if given < 2 hours from the onset of symptoms<sup>59, 61</sup>. When administered < 1 hour after onset of symptoms, a 50% mortality reduction is achieved<sup>62</sup>. It has been estimated that for every 30 minutes of reperfusion therapy delay, the patients life will be shortened by approximately one year<sup>63</sup>.

However, recently published guidelines from ESC<sup>2</sup>, recommend that in patients with STEMI, primary PCI should be the treatment of choice in patients presenting to a hospital with PCI facility. The superiority of primary PCI over fibrinolysis seems to be especially clinically relevant for the time interval between 3 and 12 hours after onset of symptoms. Within the first 3 hours, both reperfusion strategies seem equally effective in reducing infarct size and mortality. Therefore fibrinolysis is still a viable alternative to primary PCI, if it can be delivered < 3 hours after onset of symptoms. After successful fibrinolysis, the use of routine coronary angiography within 24 hours, and PCI, if applicable, is recommended to improve patients' outcome<sup>2</sup>. Thus "time is muscle" is valid in STEMI patients in the choice of either type of reperfusion.

## **Delay in suspected acute myocardial infarction patients**

Approximately one to two thirds of all patients suffering an acute MI die outside hospital, secondary to ventricular fibrillation<sup>64-67</sup>. These fatalities most commonly occur within the first hour after onset of symptoms<sup>59, 68-71</sup>, and are preceded by symptoms such as chest pain and breathlessness for longer than about 15 minutes in 70% of the patients<sup>65</sup>. The recognition of the time-dependent progression of necrosis in the heart muscle, constitutes the basis for the Swedish, as well as the international, guidelines stating that MI patients' decision time should not extend beyond 45 minutes and that reperfusion therapy, with fibrinolysis or PCI, should be performed as soon as possible, i.e. < 90 minutes after the onset of symptoms<sup>7, 12, 72</sup>. Unfortunately far from all patients seek medical care in line with the guidelines, and the time interval from symptom onset to treatment in STEMI patients varies between 2.5-6 hours in different populations<sup>73-78</sup>.

Public educational programmes aiming to reduce patient delay have had variable degrees of influence on individuals behaviour<sup>79-85</sup>, suggesting that this kind of intervention do not give any lasting effects on delay times<sup>86</sup>. The only two recent studies, one conducted in Sweden<sup>84</sup> and one in Switzerland<sup>83</sup>, that achieved a significantly shorter delay after a campaign, had longer delay times at baseline compared to the other studies<sup>79-82, 85</sup>. There is further no clear evidence that this kinds of intervention increases ambulance use<sup>79, 83, 87</sup>. Only two public interventions have shown increased ambulance use after the campaign was carried out<sup>81, 85</sup>, and both started with a level of ambulance use below 30% at baseline. However, most of the public educations carried out have been attempted over a relatively short period and it seems that a longer more intensive educational effort is needed if any lasting behavioural changes should be reached in the public<sup>86</sup>.

### **Phases of delay**

Delay time is usually defined as the amount of time between the first awareness of symptoms and arrival at the hospital. Given the recent possibilities for paramedics to treat MI patients with active anti-ischaemic and anti-thrombotic treatments already prior to hospital admittance, it is more relevant to speak about total delay time, which is the interval from the onset of symptoms to the initiation of reperfusion therapy (with fibrinolysis or primary PCI). There are three major phases with risk for delay: (1) patient decision phase, (2) transportation phase and (3) hospital phase.

### *Patient decision phase*

The patients' recognition and action phase encompasses the time elapsing between onset of acute symptoms to accessing Emergency Medical Transportation (EMT) or to initiating travel to the hospital by private transport alternatives. This phase includes action taken by the patients and those around them in response to the symptoms and signs of an MI. This phase begins when the patient becomes aware of that something is wrong. Patients may engage in a variety of behaviours that can increase or decrease time during this phase. They may decide to seek medical care at once; decide to wait and periodically evaluate or self-treat their symptoms; or decide to seek consultation from friends, relatives or medical personnel. The patient delay time constitutes the major part of the total delay time, in Swedish studies between 2 and 3 hours<sup>88</sup> and has been reported to represent 50-66% of the time between onset of symptoms and arrival at hospital<sup>89,90</sup>. The greatest opportunity of reducing the total time of delay thus lies outside hospital and the domain of responsibility of the medical care services.

### *Transportation phase*

For EMT, this phase is defined as the interval from calling the emergency service number to the arrival of the ambulance at the hospital. Its components are public access, EMT professional response, and transportation. However, the transportation time is usually of minor significance in non-rural areas. For private transportation, this phase is defined as the interval from the decision to go to hospital to arrival at the hospital.

### *Hospital phase*

This is the time interval between arrival at the hospital and start of treatment with reperfusion therapy. After arrival at the ED, substantial delays may occur before the physician makes the diagnosis of MI and implements definitive care. This phase includes patient admission procedures, initial medical examination and diagnostic procedures. Several different kinds of measures have been performed to decrease this time interval. One of the most effective strategies to decrease this phase has been to bypass the ED for patients arriving by ambulance, i.e. direct admission to the CCU or the PCI laboratory. Others have introduced specialist nurses at the ED, so that they can take an active role in rapidly obtaining and interpreting the ECG and initiating early medical treatment. Data from the Swedish National Registry for CCU hospitalised patients (RIKS-HIA) show that a decrease in delay times, from "onset of symptoms to start of fibrinolysis", has occurred by 40 minutes, from 190 minutes 1995 to 150 minutes in 2004. However, the "time from

onset of symptoms to ED arrival”, as well as the “time from onset of symptoms to arrival at the CCU” remains unchanged; approximately 120 minutes respective 150 minutes. The major reason for the decreased “onset of symptoms to treatment time” of 40 minutes is caused by the introduction of pre-hospital fibrinolytic therapy possibilities, as the time from pre-hospital ECG to fibrinolytic treatment has been just 30 minutes during the whole period this time intervals has been registered, between the years 2002 and 2004 <sup>91</sup>.

### **Factors associated with patient delay**

It seems that many factors affect decision times in patients seeking medical attention with a suspected acute MI. A review of the literature elucidates that the following factors all contribute to patient delay: (1) medical history, (2) socio-demographic factors, (3) symptom interpretation and (4) consulting others.

#### *Medical history*

Many patients who delay seeking medical treatment are at known risk of IHD and are being treated for one or more conditions related to that risk, e.g. hypertension <sup>56, 58, 92-94</sup>, angina pectoris <sup>95, 96</sup> and diabetes mellitus <sup>58, 74, 89, 93, 95, 97, 98</sup>. It has been noticeable in several studies that a previous history of MI does not decrease delay times <sup>58, 74, 75, 92, 99</sup>. The findings are however inconclusive since others have found that patients experiencing their second MI have shorter delay times than those without previous MI <sup>93, 95, 100, 101</sup>.

#### *Socio-demographic factors*

The evidence regarding the effect of age on patient delay time is conflicting, with some studies suggesting that age > 65 years <sup>58, 94, 97, 98, 102</sup> is associated with an increase in delay time, while some researchers report that age does not affect delay time at all <sup>103, 104</sup>. The few studies that have been conducted among members of other socio-cultural groups than Caucasian males and females indicate that belonging to a minority group <sup>105-107</sup> may be a reason for delaying. Finally, women <sup>58, 92, 94-97, 108</sup> also seem to delay seeking medical care. However, conflicting findings are reported on the role of gender in influencing delay, and others have reported no such relationship <sup>109, 110</sup>. Women have been found to underestimate the significance of chest pain because they are perceived to be at less risk of heart disease compared to men <sup>105</sup>. Additionally, women have also been found to be reluctant to make a visit to a physician, even when confronted with extreme discomfort, because they

feared being viewed as a worrier or hypochondriac<sup>111</sup> and that reporting their chest pain wasted the doctors' time<sup>105</sup>.

### *Symptom interpretation*

Incorrect interpretation of symptoms has been found to be a critical factor for a prolonged pre-hospital phase<sup>29, 32, 38, 112, 113</sup>. Those not experiencing chest pain have been found to fail to recognise the seriousness of their symptoms, resulting in a delay in treatment at the ED, or being misdiagnosed when they do seek treatment<sup>114</sup>. One of the most critical factors influencing delay is the recognition by patients and others that the symptoms are related to the heart<sup>104</sup>. When there is a mismatch between previous experience of or knowledge about MI and the current symptoms, it makes it even more difficult to decide to go to hospital immediately, because the patients do not interpret the symptoms as originating from the heart<sup>115-117</sup>. Delay times also increase when patients choose to wait and see if the symptoms go away<sup>118, 119</sup>. Non-delayers seem to be more likely to see themselves as potentially at risk, being able to describe a wider range of symptoms of an MI, and are much less likely to self treat their symptoms<sup>113</sup>. Individuals who focus on the likelihood of other illnesses delay significantly longer<sup>38, 76, 113, 116, 120</sup>.

### *Consulting others*

Most individuals who experience cardiac symptoms consult someone, be it a layperson or a health care professional, prior to seeking hospital treatment<sup>116, 121-125</sup>. However, individuals have also been found to be worried about asking others for help<sup>38</sup>, as well as being concerned about wasting the EMT's time and resources<sup>116</sup>. Older people are significantly more likely than their younger counterparts to report that others made the decision to go to hospital for them<sup>123</sup>. As early as 1969, the role of a layperson initiating the decision to seek help was identified as significant<sup>126</sup>. The influence of a spouse was seen to be less successful in reducing delay than that was of somebody else. It was reported that a friend or stranger was the most influential person in reducing delay. This finding has been supported in later research, which demonstrated that when a friend, stranger or co-worker assisted the patient in the decision to seek medical care, delay time was greatly reduced, as compared to the influence of a spouse<sup>102, 127, 128</sup>. However, women seem to be less likely to consult someone because they do not want to trouble others<sup>129</sup>.

## **Pre-hospital care for patients with acute myocardial infarction**

The EMT service provides access to defibrillation, emergency drugs and fast transportation to the hospital. However, many patients do not follow advice by contacting the EMT service. Studies have shown that 20% to 70% of all patients with chest pain arrive at the hospital by ambulance <sup>130-133</sup>. When this thesis was planned in 2000, 65% of the Swedish MI patients admitted to CCU arrived by ambulance. Data for 2005 demonstrate unchanged proportions of the ambulance utilisation <sup>91</sup>. Patients arriving by ambulance are different in terms of demographics and clinical characteristics from those who arrive by other means; the callers are older, more often women, have a higher prevalence of previous cardiovascular diseases, and suffer from more severe symptoms <sup>134-136</sup>. They also have a higher in-hospital mortality, larger infarcts, and more problems with congestive heart failure <sup>134</sup>. Studies have reported that the main reason for not using EMT is that patients think their symptoms do not warrant calling an ambulance <sup>136, 137</sup>, or that it is easier to take a taxi or be driven by someone else <sup>137</sup>.

The majority of ambulances in Sweden today have ECG-possibilities and telecommunication with the hospital, since a large proportion of the work of paramedics is to care for patients who suffer from suspected acute MI. Pre-hospital initiation of fibrinolytic therapy by paramedics has been shown to be both feasible and safe <sup>138</sup> and studies have demonstrated the ability of paramedics to identify ECG changes suggestive of a STEMI <sup>139, 140</sup>. When the paramedics care for a patient with a suspected acute MI, an ECG is taken and transmitted by the mobile telephone network to the CCU and a checklist regarding contra-indications for fibrinolysis is filled in. It is thus possible, after a telephone decision from a cardiologist, to start early pre-hospital treatment with fibrinolysis or GPIIb/IIIa-inhibitors by way of preparation for direct PCI.

## **Rationale for the thesis**

When planning for this thesis in 2000, there were studies available regarding demographic and clinical factors describing pre-hospital management and delay times in patients with MI. However the results were inconclusive and usually retrospective, based on medical records or registries. Studies focusing on the patients' own experience were few. Only one Swedish survey study on pre-hospital delay existed and the majority of studies were carried out in the United States. In addition, earlier studies had mostly included the patients with diagnosed MI excluding those experiencing chest pain without MI. Neither were the reasons for not using ambulance transportation among the MI population entirely understood. Lacking from this research field was also the spouses' experience, when a partner suffered an acute MI. Thus we planned this thesis to cover for some of the missing knowledge concerning patient decision phase, pointed out above.

## **AIMS OF THE STUDY**

The overall aim of this thesis was to describe patients' and spouses' experiences of suspected acute myocardial infarction in the pre-hospital phase.

The specific aims of the different papers were the following:

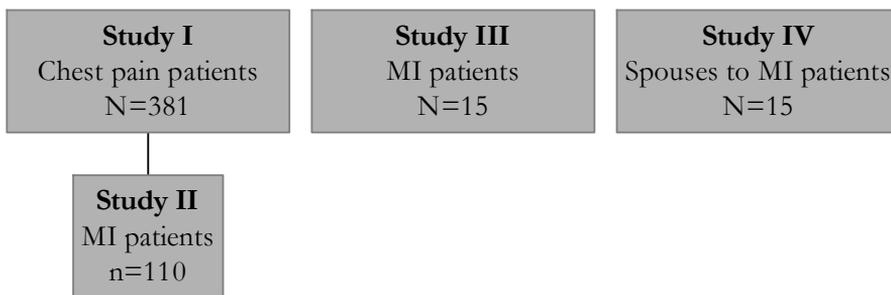
- I Describe symptoms, symptom management, and patient delay times in patients seeking treatment for a suspected myocardial infarction, and to find explanatory factors influencing the decision time.
- II Explore the choice of transportation mode when individuals experience symptoms of acute myocardial infarction.
- III Describe variations in how individuals perceived suffering an acute myocardial infarction.
- IV Describe spouses' conceptions of the pre-hospital phase when their partners suffered an acute myocardial infarction.



## SUBJECTS

### Study population

In this thesis, three groups of patients and spouses of MI patients admitted to the CCU at one University Hospital in Sweden constitute the study population: Unselected chest pain patients (**I**), MI patients (**II, III**) and spouses of MI patients (**IV**). The distribution of the study population is shown in Figure 2 and the demographic characteristics of the subjects are presented in Table 1.



**Figure 2. Distribution of the study population**

**Table 1. Demographic characteristics of the subjects in studies I-IV**

	Number	Mean age (range)	Men (n)	Population
<b>Study I</b>	381	62 (19-86)	216	Chest pain patients
<b>Study II</b>	110	67 (36-86)	73	MI patients
<b>Study III</b>	15	69 (41-83)	9	MI patients
<b>Study IV</b>	15	60 (39-91)	7	Spouses of MI patients

### Study I

A total of 403 consecutive CCU patients with symptoms of a suspected acute MI were asked if they wished to participate in the study. Twenty-two patients (5%) who fulfilled the entry criteria declined to participate. These patients did not differ from the study patients with respect to their final diagnosis. A total of 381 patients completed the study. Distribution of the final diagnoses of the patients, based on

the definitions stipulated in the ESC guidelines from 2000<sup>3</sup> was: 29% with acute MI, 21% with angina pectoris and 50% with a non-ischaemic chest pain. Myocardial infarction was objectively verified by ECG and/or by elevation of biochemical markers (CK-MB > 6µg/L, troponin-T > 0.10µg/L). In the present study, the patients within the angina pectoris group represented both stable and unstable angina patients. The baseline characteristics of the patients are listed in Table 2.

**Table 2. Baseline characteristics of the study patients upon admission to the Coronary Care Unit (I)**

Characteristics	All patients N=381	Myocardial infarction n=110	Angina pectoris n=79	Non-ischaemia n=192
Age (mean)	62	67 ††	65 †††	59
Gender, male (%)	57	66 * †	52	53
Marital status, single (%)	27	26	29	26
Educational level, compulsory school (%)	47	56 †	53	39
Current smoker (%)	18	21	14	17
Hypertension (%)	36	47 ††	43 †	27
Diabetes mellitus (%)	13	20 * †	10	9
Previous angina pectoris (%)	35	32 ***	67 ††	24
Previous myocardial infarction (%)	23	23	34 †	18

\* MI *v* Angina \* p<0.05 \*\*\* p<0.001 † MI *v* Non-ischaemia †† p<0.01 ††† p<0.001

‡ Angina *v* Non-ischaemia † p<0.01 †† p<0.001

## Study II

A total of 110 acute MI patients were included, in order to explore the choice of transportation mode to the hospital. The material is parts of the material from study **I**, representing the MI patients (29%).

The baseline characteristics of the patients in study **II** are listed in Table 3. The patients with ST-elevation were younger (p<0.01) and had more frequently a history of smoking (p<0.05), compared with the non ST-elevation patients. Otherwise no significant differences regarding baseline characteristics and infarct size were found. Previous infarction was reported in 23% of all the cases. The median age in the total group was 69 years, the same in men and women, with 66% being male (n=73) and 34% being female (n=37).

**Table 3. Baseline characteristics of the myocardial infarction patients upon admission to the Coronary Care Unit (II)**

Characteristics	All patients N = 110	STEMI patients n = 64	NSTEMI patients n = 46
Age (median)	69	65 *	71
Gender, male (%)	66	70	61
Marital status, single (%)	26	20	35
Educational level, compulsory school (%)	56	56	57
Hypertension (%)	47	45	50
Current smoker (%)	21	28 *	11
Diabetes mellitus (%)	20	22	17
Previous angina pectoris (%)	32	28	37
Previous myocardial infarction (%)	23	22	24

STEMI = ST-Elevation Myocardial Infarction,

NSTEMI = Non ST-Elevation Myocardial Infarction, \*  $p < 0.05$

### Study III

Fifteen patients with acute MI were strategically selected in order to ensure a large degree of variation in the sample. All patients who were asked to take part in the study agreed to participate. The theoretical variables were: Gender, age, previous cardiac condition (suffered an MI or not), time spent in the pre-hospital phase (delayers or non-delayers), context when the symptoms first occurred (at home or not), transportation mode to hospital (ambulance or private transportation) and final diagnosis (STEMI or NSTEMI) (Table 4). The characteristics chosen were those that have been shown to be of importance for acute MI patients' decision making when seeking medical care in previous studies<sup>58, 94, 98, 141</sup>. Transcripts resulted in a total of 225 double-spaced pages.

**Table 4. Characteristics of patients included in study III**

Characteristics	Number (N=15)
<b>Gender</b>	
Male / Female	9 / 6
<b>Age (years)</b>	
Mean / Range	69 / 41 - 83
<b>Transportation mode to hospital</b>	
Self-transportation / Ambulance	11 / 4
<b>Context, when falling ill</b>	
At home / Not at home	12 / 3
Alone / Not alone	4 / 11
<b>Delay times</b>	
≤ 1 hour	5
1-6 hours	6
≥ 6 hours	4
Range	15 minutes - 5 days
<b>Final diagnosis</b>	
STEMI / NSTEMI	11 / 4

STEMI = ST-Elevation Myocardial Infarction,  
NSTEMI = Non ST-Elevation Myocardial Infarction

## Study IV

A total of fifteen spouses of patients suffering an acute MI, were included in this study. Strategic sampling was used in order to achieve the maximum variation among informants. The following theoretical variables were regarded as important: Gender, age, time spent in the pre-hospital phase (delayers or non-delayers), transportation mode to hospital (ambulance or private transportation) and final diagnosis of the affected partner (STEMI or NSTEMI) (Table 5). Seven men and eight women, aged from 39 to 91 years, participated. None declined to take part in the study. Transcripts resulted in a total of 163 double-space pages. The length of the pre-hospital phase varied between 20 minutes and six days, with eight couples travelling to the hospital by ambulance. Ten partners developed a STEMI at the CCU.

**Table 5. Characteristics of the spouses included in study IV**

<b>Characteristic</b>	<b>Number (N = 15)</b>
<b>Gender</b>	
Male / Female	7 / 8
<b>Age (years)</b>	
Mean / Range	60 / 39 - 91
<b>Mode of transportation to hospital</b>	
Self-transportation / Ambulance	7 / 8
<b>Delay times</b>	
≤ 1 hour	3
1-6 hours	5
≥ 6 hours	7
Range	20 minutes - 6 days
<b>Final diagnosis received by the affected partner</b>	
STEMI / NSTEMI	10 / 5

STEMI = ST-Elevation Myocardial Infarction,

NSTEMI = Non ST-Elevation Myocardial Infarction



## METHODS

### The quantitative studies (I, II)

#### Design and data collection

Studies **I** and **II** had a descriptive design and a self-administered questionnaire was used for data collection in both these studies. The patients completed a questionnaire regarding the symptoms and thoughts they had, as well as actions they performed before their present hospitalisation (Appendix A, in Swedish). Clinical data, such as information on diagnosis, as well as ECG results and biochemical markers, were collected from the medical records (Appendix B, in Swedish). Study **II** also included a 1-year follow-up regarding re-hospitalisation due to recurrent MI. Deaths during the year following admission to the CCU were obtained from the Swedish National Registry of Death. All patients alive after one year were interviewed over the phone and asked whether they had been re-hospitalised and if they went to hospital by ambulance (Appendix C, in Swedish). Additionally, all medical records were then evaluated in order to determine diagnosis. Data were collected within the CCU setting, between July 2000 and March 2001.

#### The Instrument

The self-administrated questionnaire used in studies **I** and **II** was a modified version of a Swedish questionnaire that had been developed to measure how patients with MI described their symptoms and actions in the pre-hospital phase, including the choice of transportation mode to the hospital. The original questionnaire was used in a survey study conducted before a public mass media campaign in Gothenburg in the late 1980s aiming to reduce delay and increase ambulance use in society<sup>88, 137</sup>. This questionnaire was the only instrument available in Swedish at the time of planning studies **I** and **II** but was updated and developed further in collaboration with the original developers. Some questions from the original version were rephrased, based on the experience from the previous study. New reply alternatives were added to some of the questions, since it had been noted by the original developers that the existing choices were not sufficient to cover all aspects. In addition to this, one new question regarding prodromal symptoms was added. This modification was based on the growing body of knowledge<sup>142</sup> that the majority of the MI population have prodromal symptoms that they initially ignore and that this may add to delay. Further, some questions

were added from an American instrument, the Response to Symptoms Questionnaire<sup>104</sup>; a questionnaire developed in the 1990s designed to obtain information about patient delay and factors contributing to delay. This instrument has been frequently used, mainly in the United States<sup>38</sup>, but has not yet been translated into Swedish and validated in a Swedish population.

The modified questionnaire, shown in Swedish in Appendix A, had both multiple choice and yes or no answers and includes four domains with 38 items: (1) symptoms; (2) course of events; (3) means of transport to the hospital; and (4) baseline characteristics. Questions regarding symptoms address, for example, how the patients experienced the symptoms and from where they thought the symptoms originated. The patients were also asked to rate the severity of the pain or discomfort they experienced on a 10-point visual analogue scale (VAS) where "0" represents no pain; "1-2" mild pain; "3-4" moderate pain; "5-6" medium severe pain; "7-8" severe pain and "9-10" unbearable pain. In the second domain, the patients answered questions about what the bystanders did, what the dominating reason was for the decision to go to hospital, how long they waited before they decided to go to hospital, and if delaying, what the cause for that was. In the third part regarding means of transport to the hospital, patients were asked to answer how long they had waited before they decided to seek medical care, if they had used ambulance or not and what the reason was for self-transportation if this was the case. Variables regarding baseline characteristics were, for example, age and gender, marital status and location of residence, educational level, nationality and earlier diagnosed cardiovascular-related risk factors. Patient decision time was defined as the interval between "time of initial symptoms" until "time of decision to seek medical care", based on the patients' own statements. Patients were instructed to be as specific as possible when determining the time of the onset of symptoms. The transport time to hospital was not included in this interval.

Content-related validity examines the extent to which the questionnaire included all relevant, major elements to the construct being measured<sup>143</sup>. For this questionnaire, it was established by one group of clinicians for the original version and one group of clinical researchers (nurses and physicians) for the modified version, both groups specialised in acute cardiac care. Both the original version of the questionnaire and the modified version used in this thesis were based on extensive literature reviews. Additionally, a pilot study (n=10) was carried out to test user-friendliness and content in the modified questionnaire. The patients filled in the questionnaire during the first days after their MI and were also interviewed

about how they perceived all the questions. The pilot study confirmed that user-friendliness and content were at a satisfactory level and that no changes to the questions were needed. To test stability, test-retest were assessed in six patients enrolled in study **I**, by having the patients complete the instrument twice, the second time within 24 hours of the first. There was 90% agreement between the two measures.

## **Data analysis**

A delayed patient decision time was defined as > 1 hour and was selected based on data supporting maximum efficacy of fibrinolysis given within 2 hours of the onset of symptoms<sup>144</sup>. Administration within two hours at hospital can only be achieved if pre-hospital delay time is one hour or less.

Descriptive statistics were used to present the patient's characteristics. The material in study **I** was analysed, both for the group as a whole and divided into three diagnosis groups: MI, angina pectoris and patients without ischaemia. Comparisons were made by Chi-square and Fisher's exact test. Continuous, not normally distributed, variables were tested using Mann Whitney U-test. All tests of statistical significance were two-tailed and probability values of  $p < 0.05$  were considered to be significant (**I**, **II**). A multiple binary logistic regression (Enter method) was used to determine the relationship between various patient-related factors with the probability of causing delay (**I**) or not using ambulance (**II**). The model was constructed by using the logistic regression procedure available in SPSS (SPSS version 11.0, SPSS Inc, Chicago, USA). Factors included in the regression analysis were those which had significant influence on delay times, or utilisation of ambulance, in the univariate analysis. The odds ratios and 95% confidence interval were calculated directly from the estimated regression coefficients and were used as a measure of association between delay, or ambulance utilisation, and the factors included in the analysis, in the material in studies **I** and **II**, and not used as a general measure of the relative risk for delay or underutilisation of the EMT services.

## **The qualitative studies (III, IV)**

### **Design and data collection**

In studies **III** and **IV** a qualitative design was employed and the data were collected through semi-structured interviews, in order to make it possible for the patients and spouses to describe in their own words how they perceived the course of events in the pre-hospital phase. In order to commence the conversation, the following introductory question was used: "Describe what happened when you (your partner) suffered your (his/her) infarction". This constituted the basis for gathering data. Follow-up questions were asked to deepen, further develop or clarify the narratives, for example: "Can you develop that further?"; "How did you think then?"; "How was that?". The interview was completed by the interviewer asking: "Is there anything else that you would like to tell me about what happened when you suffered your MI, which we have not have been talking about". All interviews were taped and transcribed verbatim. The interviews were conducted between May 2003 and January 2004 (**III**), and between February and November 2005 (**IV**).

### **Data analysis**

The data were analysed using a phenomenographic research approach, which has been in use for almost three decades, mostly in pedagogical research. The approach was developed by a group led by Marton in the 1970s at the Department of Education at Gothenburg University, Sweden <sup>145</sup>. Early research was described using an empirical approach, dealing with issues related to learning <sup>146</sup>, but has since then been developed towards a theoretical framework with several studies focusing on health-care issues <sup>141,147</sup>. The word "phenomenography" has its roots in Greek "phainomenon" and "graphein", which translated to English, mean "appearance" and "description". The combination of these two words makes phenomenography a description of appearances <sup>148</sup>.

Phenomenography is empirically grounded; aiming to identify qualitatively different ways in how individuals experience, conceptualise or understand various kinds of phenomena in the surrounding world <sup>145</sup>. Understanding, or experiences as conceptions, is central in phenomenography and is the unreflecting basis, created by experience, on which different opinions rest <sup>149</sup>. Phenomenography is described by Marton <sup>146</sup> as non-dualistic, as the assumption is that the only world that we can

communicate about is the world as experienced and that people differ as to how the world is experienced, but these differences can be described, communicated and understood by others. Such descriptions of variations with differences and similarities in how the world is perceived and what meanings people ascribe to the specific situation, constitute the most essential outcomes of phenomenographic research, and are usually illustrated as different categories in order to describe this variation<sup>141, 146</sup>. The area of interest is not the phenomena/experience itself, with people describing things as they are (first order perspective), but the individuals' understanding or conception of a certain aspect of the world, i.e. how things appear to people to be (second order perspective)<sup>146, 150</sup>. According to Marton<sup>146</sup>, a person's way of experiencing something is also related to how their awareness is structured. It involves both a "what" and a "how" aspect, with the "what aspect" corresponding to the object itself, which implies that when people experience something, they are mostly oriented towards something that is perceived as important to them. The "how aspect" is related to the act and the structure of the experience described and consists of the structural and meaning aspects.

#### *The phenomenographic analysis procedure*

The analyses in studies **III** and **IV** comprised the seven steps described by Dahlgren and Fallsberg<sup>151</sup>. In the analysis, similarities and differences between individuals were sought; conceptions were separated from individuals, and yielded categories and sub-categories of how the pre-hospital phase was perceived by the patients and spouses. There was a constant interplay between the various steps of the analysis. The procedure is illustrated by examples from the analysis in study **IV**.

I. *Familiarisation*. Obtaining an overall impression of the material, every interview was listened to and read through a number of times.

II. *Condensation*. The analysis was followed by identification and reduction of significant individual statements, to give a short description of what the spouses had narrated. It was important for the researcher to focus on what the spouse had discerned as being important. To do so, questions were introduced into the text and were expressed, e.g. as, "What is this spouse trying to say regarding his/her partner's symptoms?"

III. *Comparison*. The selected statements were compared, in order to identify sources of differences and similarities. Several questions were addressed in the text by the researcher, e.g. "What is considered important to the spouse concerning the pre-hospital phase?" This question facilitated identification of the "what-aspect".

Moreover, questions such as, “Why and how is this important for the spouse?” were posed in order to help the researcher in identifying the “how-aspect”. The process of comparing statements between the spouses was facilitated by the question: “Is this statement similar or different from statements expressed by other spouses concerning this specific part?”

IV. *Grouping*. The statements describing the same characteristic traits were put together and placed into one of 12 preliminary sub-categories.

V. *Articulating*. This step involved a preliminary attempt to describe the condensed meaning of the statements within each preliminary sub-category, aiming to establish borders between the categories distinctly separated from one another.

VI. *Labelling*. Through a comparison between the whole and the parts, the focus of attention was shifted from relationships among the different conceptions within the sub-categories to instead establishing borders between the sub-categories. This step entailed revision of the preliminary sub-categories several times, in order for them to be considered satisfactory. Some overlap was found during this comparison and the 12 preliminary sub-categories were subsequently reduced to nine. Each sub-category was named using a suitable linguistic expression.

VII. *Contrastive comparison*. Finally, the analysis process was completed by bringing together the unique sub-categories illustrating the same dimension of conception into an outcome space of two categories.

In accordance with Marton<sup>145</sup>, an independent person having considerable experience in acute cardiac care and experience of qualitative research, sorted 1/3 of the conceptions from studies **III** and **IV** in order to test the categorisations. Generally, inter-subjective agreement ranges between 65 and 100%<sup>149</sup>. Additionally, Cohen's Kappa was used to assess the inter-rater reliability. Kappa is considered to be an improvement over using % agreement when evaluating this type of reliability. Kappa has a range from 0-1.00, with larger values indicating better reliability. Generally, a Kappa > 0.70 is considered satisfactory<sup>152</sup>. In study **III**, an 81% level of inter-subjective agreement (K=0.78) in the sub-categories was reached, with 92% in the categories (K=0.87). Whereas in study **IV**, an inter-subjective agreement was reached in 74% of the sub-categories (K=0.71), and 92% of the categories (K=0.83).

## ETHICAL ISSUES

All studies were approved by the Regional Ethics Committee for Human Research at the University of Linköping, Sweden, and conforms with the principles outlined in the Declaration of Helsinki<sup>153</sup>.

**Studies I-II** Informed consent was obtained from all subjects, who were informed both in writing and verbally. Patients were haemodynamically stable and pain free when they were asked to participate within 24-72 hours after their admittance to hospital. They had the opportunity of, whenever they so wished and without the need to give any reasons, choosing not complete the survey and withdrawing their participation in the study. The answers were treated confidentially by use of code-numbers and the analysis was carried out on a group rather than individual level.

**Study III** Informed consent was obtained from all patients prior to inclusion and also before interviews were taped. In order to enable recall of events, which led to the hospitalisation and for estimation of delay times, all interviews were conducted within 24-72 hours after hospitalisation. This time frame was chosen to allow the patients to become haemodynamically stable and pain-free, while simultaneously not allowing too long time to elapse between hospital admission and the interview.

**Study IV** Informed consent was obtained from all spouses prior to inclusion and also before interviews were taped. Additionally, all the affected partners who had suffered an MI were informed that the interviews would be carried out. All interviews were conducted within 24-48 hours after hospitalisation, to ensure the affected partner had become haemodynamically stable and pain-free. This, in turn, ensured that the spouse would not be in a state of personal crisis, while at the same time not allowing a too great time lapse between the partner's admission and the interview.



## RESULTS

### Review of the papers

#### Delay in patients with suspected myocardial infarction (I)

The aim of this survey study in 381 patients was to describe symptoms, symptom management, and patient delay times in patients seeking treatment for a suspected myocardial infarction, as well as to find explanatory factors influencing the decision time.

The results showed that 84% of the patients suspected that the symptoms in some way emanated from the heart and the dominating reason for this was a history of angina pectoris (38%) or a relative who had had an MI (30%). In 69% of the patients, chest pain was the main reason for going to the hospital. The study patients were divided into three groups: MI patients (n=110), angina pectoris patients (n=79) and non-ischaemic patients (n=192). The patients with MI (n=110) differed in some respects from the other patients when interpreting their symptoms. Seventy-four percent of the patients with MI suspected that the symptoms emanated from the heart and 34% interpreted their symptoms as an incipient MI, compared to the other patients (angina pectoris and the non-ischaemic patient; 12% each,  $p<0.001$ ). The occurrence of chest pain ( $p<0.001$ ) and nausea ( $p<0.001$ ) were the symptoms that significantly differed between patients with and without MI but one fifth of the patients with MI did not experience chest pain at all. The non-ischaemic patients described stabbing pain significantly more often (12%) compared with the patients with MI (2%,  $p<0.01$ ). The patients with MI reported a severe to unbearable pain (measured as  $\geq 7$  cm on the visual analogue scale), more frequently (61%) than the patients with angina (41%,  $p<0.05$ ) and the patients without ischaemia (33%,  $p<0.001$ ).

More than half (54%) of the total of 381 patients stated that they had not hesitated to go to the hospital, when 59% had actually delayed going to the hospital  $> 1$  hour after the onset of their symptoms. However, when the patients with and without MI were compared, there were significantly more patients with MI who sought care sooner ( $< 30$  minutes) and were less likely to have longer delays. The most frequently given reason for the patients with MI delaying further after making the decision to go to hospital, was that they were not aware of the importance of a short decision-time (32%). A total of 44% called EMT and went by ambulance to

the hospital. As shown in Table 6, a frequent action taken in response to their symptoms was, e.g. to consult their spouse (59%) and/or the general practitioner (GP) (33%) initially.

**Table 6. Initial response to symptoms of a suspected acute myocardial infarction. All numbers represents percentages.**

<b>Response</b>	<b>All patients N = 381</b>	<b>Myocardial infarction n = 110</b>	<b>Angina pectoris n = 79</b>	<b>Non-ischæmia n = 192</b>
<b>Medication to relieve symptoms*</b>	<b>n = 378</b>	<b>n = 109</b>	<b>n = 79</b>	<b>n = 190</b>
Acetylsalicylic acid	7	9	5	7
Other pain killers	11	9	10	12
Nitrates	33	36	58	22
Other medication	2	2	1	3
No medication	48	48	28	57
<b>Initial consultation</b>	<b>n = 377</b>	<b>n = 108</b>	<b>n = 78</b>	<b>n = 191</b>
Spouse	59	59	51	61
Child	6	8	4	5
Friend	7	8	4	7
General practitioner	14	10	22	14
Emergency services	8	11	11	6
Other person	5	4	5	7
Did not contact anybody	1	-	3	-
<b>Contact with the general practitioner</b>	<b>n = 381</b>	<b>n = 110</b>	<b>n = 79</b>	<b>n = 192</b>
Yes	33	26	38	35
No	67	74	62	65
<b>Reasons for going to hospital*</b>	<b>n = 374</b>	<b>n = 107</b>	<b>n = 78</b>	<b>n = 189</b>
Severe symptoms	45	59	47	36
Thought it was a heart attack	18	34	12	12
Thought the symptoms were heart related in origin	48	39	50	51
Thought I was seriously ill	2	2	1	2
Somebody told me to go to hospital	54	57	50	55

\*The patients had the opportunity to mark more than one alternative.

**Table 7. Univariate analysis and multiple regression analysis, including all patients and their predictors of delaying the decision to go to the hospital (> 1h)**

Delay characteristics	Univariate analysis		Odds ratio	
	n (%) N = 381	P values in univariate analysis	(95% confidence interval) n = 334 †	P values in multivariate analysis
<b>Acute cardiac condition</b>				
Myocardial infarction diagnosis	110 (29)	.006	0.72 (0.38-1.38)	.32
Prodromal symptom	53 (14)	.024	0.65 (0.32-1.34)	.26
<b>Symptoms</b>				
Oppressive feeling across the chest	210 (55)	.05	1.30 (0.76-2.21)	.34
Tiredness and/or weakness	110 (29)	.012	1.31 (0.66-2.60)	.44
Nausea and/or cold sweat	110 (29)	.037	0.92 (0.49-1.72)	.78
Dull pain	91 (24)	.001	2.12 (1.11-4.04)	.023
Troublesome symptom(s)	122 (32)	.005	1.41 (0.79-2.51)	.24
Unbearable symptom(s)	46 (12)	.009	1.41 (0.57-3.48)	.46
<b>Course of events</b>				
Those around suggested rest	57 (15)	.007	1.96 (0.89-4.34)	.10
Did not want to worry the family	34 (9)	.016	1.31 (0.48-3.56)	.60
Did not tell anybody about the symptoms	50 (13)	.018	1.84 (0.82-4.11)	.14
Never hesitated to go to hospital	206 (54)	.001	0.59 (0.33-1.06)	.08
Contacted the general practitioner	125 (33)	.000	2.81 (1.53-5.15)	.001
Contacted the emergency services	168 (44)	.001	0.45 (0.26-0.80)	.007
<b>Thoughts*</b>				
"This is nothing serious"	238 (66)	.000	2.25 (1.27-3.98)	.005
"I am going to die"	15 (4)	.002	0.48 (0.10-2.21)	.35
"This must be a heart attack"	68 (18)	.000	0.66 (0.33-1.30)	.23

\* Some missing responses, which explain the differences in the percentages. † Missing responses are excluded in the regression analysis

The predictors for patient delay, > 1 hour, are shown in Table 7. The bivariate logistic regression analyses (n=334) identified three variables that were associated with a delay of > 1 hour: Dull pain, contact with a GP, and the thought that it was nothing serious. Pre-hospital delay was unrelated to the occurrence of chest pain, age, gender, marital status, educational level, and a history of MI, angina pectoris, diabetes mellitus, or hypertension in this undifferentiated material. The only variable associated with a shorter delay was the decision to call for ambulance.

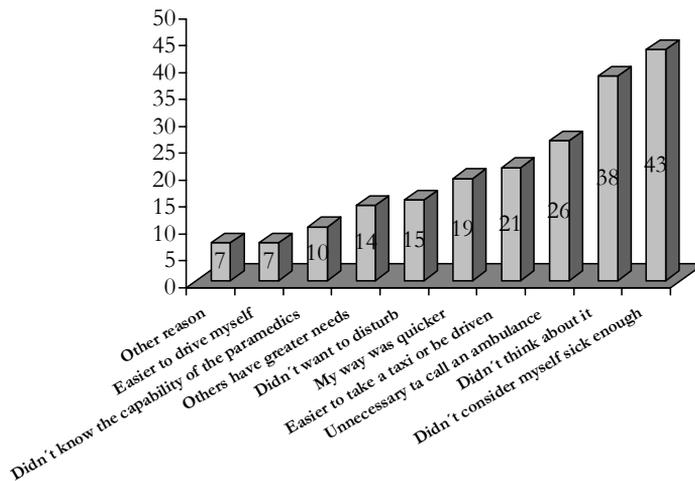
## **Ambulance utilisation in patients with myocardial infarction (II)**

The aim of this survey study in 110 MI patients was to explore the choice of transport mode when individuals experience symptoms of acute MI.

The results showed that 60% arrived at the hospital by ambulance, which represented 68% of the women and 59% of the men (ns), but only six patients called the emergency number themselves. It was usually the spouse (40%), or the GP (32%) who called the EMT service. Thirty-five persons (32%) used private transportation (drove the car by themselves or let somebody else drive) to obtain medical care and 7% (n=8) used public transportation (such as taxi or bus). One person came to hospital on foot. As shown in Figure 3, the most frequent reason for not choosing an ambulance was that the patient did not perceive the symptoms to be serious enough to merit a drastic action like calling the emergency number (43%). The second most common reason for not choosing an ambulance was that the patients did not think about EMT being an option (38%), whereas 26% thought it was unnecessary to call an ambulance.

Patients calling for an ambulance differed from those who did not, in several aspects. The maximum pain at home, measured on the visual analogue scale (VAS), was experienced as severe (8 cm) in the patients in the ambulance group and medium severe (6 cm) in the non-ambulance group ( $p<0.05$ ). Other medical characteristics associated with ambulance use are presented in Table 8, and show that STEMI patients ( $p<0.05$ ), and those with a history of acute MI ( $p<0.05$ ), call the emergency number significantly more often. There were no differences regarding gender or age. Additionally, patients with vertigo ( $p<0.05$ ), nausea ( $p<0.001$ ) or unbearable symptoms ( $p<0.01$ ) also chose an ambulance for transport to the hospital. The only significant reasons for not choosing an ambulance were cramp like pain ( $p<0.05$ ) and the patient perceiving the symptoms not to be serious

( $p < 0.01$ ). In a multivariate analysis, ST-elevation (OR=0.30,  $p < 0.05$ ), unbearable symptoms (OR=0.20,  $p < 0.05$ ) and nausea (OR=0.33,  $p < 0.05$ ) appeared as independent predictors of ambulance use. Only cramp like pain (OR=5.17,  $p < 0.01$ ) appeared as an independent predictor of not using an ambulance.



**Figure 3. Reasons for not choosing an ambulance (%). Patients could choose more than one alternative, which explains why the total sum is not 100%.**

Approximately half of the patients delayed by  $> 1$  hour (48%) and 40% waited  $> 2$  hours. Those who thought the symptoms were not serious ( $n=66$ ) delayed longer ( $p < 0.01$ ). Likewise, women ( $p < 0.05$ ), patients who experienced pressure across the chest ( $p < 0.01$ ), symptoms of tiredness ( $p < 0.01$ ), or other, unspecific symptoms ( $p < 0.01$ ), had prolonged decision times compared to those who did not. A total of 77% of the patients considered their symptoms to be heart-related and the patients who believed that they were having a heart attack ( $n=36$ ) had a shorter delay ( $p < 0.001$ ). Patients who called their GP had also a prolonged pre-hospital decision time, compared with those who decided to go to hospital directly ( $p < 0.01$ ). The patients transferred by ambulance however had a shorter delay ( $p < 0.05$ ). The patients suitable for reperfusion, the STEMI patients, had a shorter delay compared to the NSTEMI patients ( $p < 0.01$ ). STEMI patients choosing EMT reduced their

delay-time to reperfusion by 21 minutes as compared to the private transported patients. Median time from onset of symptoms to fibrinolysis was 2 hours and 30 minutes (n=37) in the STEMI group, and 2 hours and 33 minutes for STEMI patients undergoing PCI (n=17).

**Table 8. Univariate analysis of ambulance use in relation to age, socio-demographic variables, acute cardiac conditions and clinical history of the patients with myocardial infarction. All numbers represent percentages.**

Characteristics	Ambulance n = 68	Self-transport n = 42	p-value
<b>Socio-demographic variables</b>			
Age, ≥ 65 years	65	48	0.11
Gender, male	63	71	0.41
Marital status, single	29	21	0.38
Educational level, compulsory school	63	45	0.08
Distance to hospital, ≥ 10 kilometers	47	31	0.11
Symptom onset on a weekday	74	55	0.06
<b>Acute cardiac conditions</b>			
ST-elevation	68	43	0.02
Visual Analogue Scale > 7 cm	72	49	0.02
Symptom onset > 1 hour	41	60	0.08
<b>Clinical history</b>			
Hypertension	49	45	0.85
Diabetes mellitus	19	21	0.81
Previous angina pectoris	37	24	0.21
Previous myocardial infarction	29	12	0.04

During the one-year follow-up, the mortality among the ambulance-transported patients was 8% (n=5) compared to 0% in those who did not go by ambulance (ns). Forty-two patients had been re-hospitalised with a total of 62 re-hospitalisations, divided into 10 for chest pain observation (16%), 9 for angina pectoris (14%), 14 for a recurrent MI (23%) and 29 for other not cardiac-related hospitalisations (47%). A total of 23 patients (70%), hospitalised due to chest pain (n=33), went to hospital by ambulance the second time when falling ill. However, only 11% called the emergency number themselves. Eleven of the patients that developed a new MI (n=14) went by ambulance, which is an increase of 19%.

## Patients' conceptions when suffering a myocardial infarction (III)

The aim of this qualitative study in 15 patients was to describe variations in how individuals perceived suffering an acute MI.

In the analysis, eight sub-categories showing variations in conceptions in the pre-hospital phase were identified and summarised into three categories: (1) Manageability, (2) Vulnerability, and (3) Interaction (Table 9). One selected original quotation from each category, translated from Swedish to English, is presented in a Box to illuminate the experiences of the patients.

**Table 9. Categories and sub-categories concerning the patients' conceptions of the pre-hospital phase (N=15)**

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### Categories and Sub-Categories

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#### Manageability

- Symptom awareness
- Denial of severity
- Confidence in self-care

#### Vulnerability

- Lack of control
- Experiencing anxiety

#### Interaction

- Support from those in the surroundings
  - Concerns for the family
  - Utilisation of healthcare resources
- 

**Manageability** involved a need for the patient to understand the situation and to have a similar situation to compare with, self-experienced or retold by others, thereby having knowledge that facilitated the decision about what action to take. They described a range of acute symptoms, from a sudden onset of classic acute MI symptoms with severe chest pain, radiation to the left arm, cold sweat and indisposition, to experiencing diffuse, vague and variable symptoms, such as intermittent weakness and tiredness. Some patients had prodromal symptoms with fatigue or discomfort in the chest over several hours or days; making them perceive the symptoms not to be serious or thinking that the symptoms were temporary. The patients also tried to link their symptoms to possible causes in their lives, such as increasing age, stress, pain or tiredness due to hard work, in order to explain their symptoms.

**Box 1. Manageability** – denial of severity

A man, experiencing his first MI, waited one hour before going to hospital by private transportation. He expressed the decision-process like this:

*"It's like agony over having to make the decision first, and then you think that a heart attack is so nasty and so complicated and dramatic so you prefer not to have one. You try to convince yourself that it's probably something else, right. It might pass and so on.... but if you can fool yourself, then you do that, like for a while, but you can't like do it for very long".*

The patients coped with this arising threat to their lives by denying their symptoms (Box 1). They did not deny the presence of the symptoms, but minimised their significance thereby not acknowledging the need for rapid action. The conceptions varied, ranging from denial to immediate acceptance that the symptoms

were serious. The patients also had confidence in self-care strategies, such as medication, rest, massage or intake of alcohol, in order to handle the symptoms. However, conceptions varied, from patients who tried initially to perform self-care but who turned to the healthcare services if this proved to be insufficient, to patients who did not consider it possible to do anything on their own. These patients managed their situation by immediately consulting primary healthcare or the hospital.

**Box 2. Vulnerability** – experiencing anxiety

A woman experiencing her first MI. She expressed the anxiety as a trigger for seeking medical attention immediately.

*"Suddenly I became like, well it happened like successively right, I got worse and worse and worse and then I know I thought that, Oh help, what is this, what if I'm going to die. I saw I'd be lying dead there for three days at the top of the stairs as my husband was away like for three days, but I didn't want that."*

**Vulnerability** was characterised by a lack of control and feelings of fear or anxiety, working both as triggers and barriers to taking action and seeking medical care. As symptoms continued, or became worse, patients reported how they lost the competence to make their

own decisions. A common reason for the decision to go to hospital was that the symptoms continued, but the conceptions varied and some patients reasoned that it was better to seek help immediately before symptoms worsened further. The symptoms related to the heart also caused anxiety for the patients, but the conceptions varied, ranging from feeling calm to high levels of anxiety. Anxiety emerged when strategies were ineffective in resolving symptoms, or when the symptoms experienced were perceived as severe. Anxiety was mostly related to the nature of symptoms, the more severe the symptoms, the more anxiety emerged (Box 2).

**Interaction** involved psychosocial support, as well as practical guidance from the environment and was fundamental in helping the patients manage the situation that emerged. However, experiences ranged from no layman support to endorsement of a very supportive environment, exemplified as the spouses providing medication, helping them to bed, contacting the GP, or calling the emergency number. Psychosocial support implied that the spouse was calm and tried to infuse courage into the affected partner. Others stated that they lacked support and empathy from their spouse, as well as from the EMT service and that their symptoms were not taken seriously.

**Box 3. Interaction** – utilisation of healthcare resources

A man experiencing his first MI, a STEMI. He expressed the choice of transportation mode in this detailed way.

*“The car is like the easiest and it’s just to go out and sit in it and drive off. If you’re going by ambulance it’s a process, there’s phoning, then waiting and yes them bundling you in. It’s so dramatic and taxi is a bit like hard work with the phoning, it’s so easy to just get into your own car. But then I felt I didn’t feel very well and to avoid all the other stuff it was like perfect that the guy could come and pick me up because that was like almost as simple as driving yourself. You ride with someone you know and everything. It’s well quite convenient and it’s much easier to use what you’ve already got than phoning and getting an appointment and then waiting and being at the mercy of others when you’re going to do such a thing. I want to go in with my own things and look after myself.”*

Responsibilities and concerns for the family sometimes prevented the patients from seeking medical care, but the conceptions ranged from avoiding being troublesome or worrying the family to seeing it as natural to tell the family members what was happening. Patients described ignoring symptoms, because they

felt their responsibilities to the family could not be delegated to anyone else, while others expressed how they could bear some symptoms and avoided admission, because they were afraid of disturbing the hospital. Patients also narrated how they made practical arrangements for their spouse before going to hospital.

Finally, when the situation was unbearable it resulted in a contact with the healthcare service. A common conception was that the correct action to take was to first call the GP, instead of going directly to the hospital. Regarding choice of transport, the conceptions ranged between patients’ resistance to call EMT and those who regarded an ambulance as the only alternative because they were used to contacting the EMT service, or believed themselves not to be capable of handling the situation alone. Those who hesitated to call EMT did not perceive themselves as sick enough to go by ambulance or perceived the ambulance as a too drastic action and felt that the ambulance personnel had enough to do. Others regarded

the ambulance only as a means of transport that would bring the individual to hospital as fast as possible, and not as a medical unit, thereby using a private alternative since this way was “faster” (Box 3).

## Spouses' conceptions of their partners suffering a myocardial infarction (IV)

The aim of this qualitative study in 15 spouses was to describe their conceptions of the pre-hospital phase when their partners suffered an acute MI.

Transcripts from the interviews resulted in two categories (1) Being resourceful and (2) Respecting independence, divided into nine sub-categories (Table 10). Two selected quotations from each category, translated from Swedish to English, are presented in Boxes to illuminate the experiences of the spouses.

**Table 10. Spouses' conceptions of the pre-hospital phase when their partners suffered an acute myocardial infarction (N=15)**

Categories	Sub-categories
<b>Being resourceful</b>	Sharing the experience
	Having knowledge
	Understanding the severity
	Being rational
	Consulting others
<b>Respecting independence</b>	Accepting the need for control
	Marital roles and experiences
	Restraining emotions
	Seeking agreement

**Being resourceful** contained a variation of conceptions, ranging from the spouses having the ability and the resources to meet the situation effectively, to having a feeling of powerlessness in the situation. In order to be resourceful, the spouses expressed the necessity of sharing the experience with their partner, as well as the importance of having previous knowledge of MI, which facilitated the interpretation of the seriousness of the situation. When the partner had classical symptoms of MI, the spouses interpreted the symptoms correctly. However, the spouses also expressed misconceptions regarding the cause of the symptoms, assuming that the affected partner's chest pain was caused by an incipient cold, an

**Box 4. Being resourceful – sharing the experience**

A female spouse, experiencing her partner's second MI. The couple waited almost 20 hours before they sought medical attention. This spouse felt like an outsider, since the partner did not talk about his symptoms.

*"So that then it well felt, yes it doesn't feel good that he gets up himself during the night, according to me, and not waking me up because I would have liked to have known, but he felt that I was fast asleep and decided not to wake me".*

attack of biliary colic, lung problems, or pain due to back problems, which usually lead to hesitation in seeking medical attention immediately. The spouses also expressed how a longer time could pass without being aware of what was happening, since their partners did not inform them when they first noticed the symptoms (Box 4).

**Box 5. Being resourceful – being rational**

A female spouse, experiencing her partner's second MI. She described her rational behaviour as being based on earlier knowledge.

*"I said to one of my daughters to "call an ambulance" while I myself went and got the nitroglycerine and gave it to him and made sure that he was lying down on the sofa. Then I went and got his wallet and saw that he was cold sweating. I went to the kitchen and turned off the stove, which was on to boil a kettle for tea. My other daughter went and got the car out, since she thought she was perhaps going to drive him, but I said, "No, we must wait for the ambulance, if something should happen on the way then they can help us".*

Another conception that emerged from the interviews was how the spouses felt forced to be rational because of their responsibility for the partner's well being and that they were focused on practical arrangements (Box 5). They decided which actions to take, called the EMT service, provided medication and tried to make their partner

comfortable while waiting for the ambulance. Yet, as a first measure, the spouses usually recommended that their partner rested before doing anything else. Others expressed how they lacked this intrinsic power in the situation. They experienced a mental block and did not know what to do or were completely paralysed and unable to act, thus consulting a member of the healthcare personnel or a layperson for advice. An emergency call or seeking care at the ED became the lifeline of the spouse in this frightening situation. Interactions with the GP also constituted important pathways to medical care for the spouses. Those spouses who contacted their GP, stated that they were either used to interacting with the GP on a regular basis and therefore initiated such a contact, or that they were influenced by the ongoing debate in the media aiming to persuade individuals to seek care at the right level in the healthcare sector. Almost half of the couples went to the hospital by private car, lacking knowledge about the competence of ambulance staff, or being

of the opinion that transportation would be much faster if they went to the hospital by themselves. Conceptions about ambulance being a too drastic action to take also emerged.

**Respecting independence** was characterised by how the spouses in the initial course of events respected their partner's autonomy and integrity in the situation, instead of making suggestions and taking over in deciding what to do. This consideration for the partner, even in this serious situation, had been built up in the couple's relationship over a long time. The spouses expressed confidence in their partners' competence to make their own decisions. They permitted the partner to have this sense of control in the situation because he/she expressed a need for trying self-medication or to wait and see how the situation would develop (Box 6).

**Box 6. Respecting independence** – accepting the need for control

A male spouse, experiencing his partner's first MI. He permitted the partner to have a sense of control in the situation because she expressed a need to wait and see how the situation would develop further. The couple waited at home for 6 hours.

*"Yes, I gave her the time that she asked for, and let her see how it went for a while at first, but I knew already then that this was totally wrong and that we should have gone to the hospital already before she took her outdoor clothes off. In that case we would have got away half an hour earlier."*

However, when some time had passed and the partner's condition had not improved, the spouses ignored the partner's need for control. But the conceptions varied, and others continued to seek agreement with the partner and let him/her decide what to do henceforth. Respecting independence also contained conceptions about how the

spouses tried to restrain their own emotions in front of the partner, in the belief that this would protect him/her from becoming worried or upset. They tried to be strong and infuse courage into the partner, as well as the rest of the family. Some partners were critically ill, yet the spouses tried to restrain their own emotions, not allowing their own fear to increase. However, the spouses stressed the difficulties of being a bystander, not really knowing how the partner felt.

The spouses related to earlier roles and patterns in the marriage as one important reason for respecting the partner's independence, and how this experience affected the situation. They knew the partner's personality so well and took this into account even in this serious situation.

**Box 7. Respecting independence** – marital roles and experiences

A female spouse, experiencing her partner's second infarction. She expressed how the partner's resistance to the medical services delayed the time to hospital admittance by 19 hours.

*“But it is the same with his diabetes. When he feels that he has bad blood sugar, but go to the doctor? No, he doesn't go before he is sent an appointment because he is frightened of knowing the truth, that's how it is. And then he is frightened about his heart as well, that is why he didn't want to go”.*

For example, women explained that their partners were the strong ones in the relationship, usually being the ones to decide what to do and this was the case even in the present situation. Others expressed how their partner did not usually complain over bodily ailments and, for that reason, did not complain over their current symptoms. The

spouses also explained the difficulties they had in convincing their partners to seek medical care (Box 7). In respecting their partners, the spouses wanted to discuss the situation with them, asking for permission to carry out different kinds of actions. They described how this necessity of reaching an agreement was inherent to human nature. Therefore, the spouses sought approval from their partners before they could intervene, by asking for confirmation if going to hospital was the right thing to do and if they should call an ambulance. If the spouses were not in agreement with their partners, they were afraid of bulldozing over them and thereby exaggerating their symptoms. This method of reasoning prolonged the pre-hospital phase for many of the couples.

## DISCUSSION OF RESULTS

During the most recent decades, effective reperfusion therapies have been introduced into the care of STEMI patients, with primary PCI seen as the gold standard treatment <sup>2</sup>. However, the effectiveness of reperfusion is time dependent, and if individuals suffering an acute MI are to receive the maximum benefit of the fibrinolysis or the primary PCI, they must contact the EMT services quite soon after symptom onset. Earlier studies have shown that the patients' delay time stands for about half of the time prior to treatment being started <sup>89,90</sup>, and that a large proportion of individuals die outside hospital due to ventricular fibrillation, secondary to an acute MI <sup>64-67</sup>. Lives could probably be saved if these individuals only responded more rapidly to their symptoms. Hence, the overall aim of this thesis was to describe patients' and spouses' experiences of suspected acute MI in the pre-hospital phase, including description and interpretation of symptoms, symptom management, various reasons for delay and choice of transport mode to the hospital.

### Symptom interpretation and management

As in other studies <sup>30,31</sup>, absence of chest pain was reported in a substantial proportion of the MI patients (**I**). This is a disturbing finding because chest pain has been considered the hallmark symptom of MI in the public as well as among health care professionals <sup>32,117,154</sup>. Individuals need a clearer understanding of the variability of symptoms of MI, so that they can be quicker in attributing appropriate symptoms to the heart. Earlier research has shown that there is a tendency among the elderly to dismiss mild and ambiguous symptoms as normal aging <sup>155</sup>. Unfortunately, prior stroke, heart failure, and diabetes are conditions associated with lack of chest pain, and older people are more likely to have these conditions <sup>30,38</sup>. However, we did not find any significant relationship between greater age and prolonged decision times (**I**).

Our studies (**I**, **III**) showed that a number of patients did not assess their symptoms as serious or did not consider them to originate from the heart, which has also been found previously <sup>38</sup>. One reason for this conception in our study (**III**) turned out to be that the individuals saw themselves as healthy, not being prone to cardiovascular disease. This way of minimising symptoms has earlier been found to involve the perceived absence of one or more risk factors, particularly old age and an inactive lifestyle <sup>156</sup>. Knowledge about acute MI symptoms and their causes may decrease decision time, but if the symptoms do not match earlier knowledge or

expectations, people may still delay seeking treatment<sup>157</sup>. In accordance to this, we found that when experiencing a dull pain instead of a “classic” acute severe chest pain, this prolonged the pre-hospital phase (**I**). Bleeker et al.<sup>122</sup> found that patients without previous knowledge about the range of cardiac symptoms delayed seeking medical attention, compared to those being aware of the variety of MI symptoms.

Our findings (**I, II**) are also consistent with earlier research reporting that many MI patients wait to see whether symptoms disappear because they do not consider themselves to be critically ill<sup>158</sup>, which contribute to delay. This hesitation may indicate that denial is a common reaction among patients with signs of MI and was also found in study **III**. Unfortunately, the spouses seemed to be influenced into sharing their partners' denial, not willing to confront their symptoms (**IV**). This can be one explanation why earlier research has shown that individuals falling ill in the presence of a spouse have a prolonged decision time compared to those that for example fall ill at work<sup>102, 127, 128</sup>. Someone outside of the family may be less willing to bear the responsibility of an incorrect decision and thus be less tempted to share the individual's “wishful thinking”, since they are not influenced by earlier roles and experiences. Talking about the partner as being the strong one in the relationship, used to decide, emerged as a prominent female pattern. This was a contributory reason for the spouses being passive and listening more to the partners than to themselves (**IV**). Prior studies indicate that women are more relationship-oriented and attuned to the well-being of others than men are<sup>159</sup>, and that women are more responsive to their partners' health in comparison to men<sup>160</sup>.

We also found that the patients tried various self-care strategies to handle the situation (**I, III**). Among our patients, who reported difficulties in attributing their symptoms to the heart, different self-care strategies or denial were especially conspicuous (**III**). The spouses, on the other hand, expressed how they allowed the affected partner to try self-care and how they were involved in this behaviour themselves, by organising rest or providing medications, rather than quickly recommending the partner to seek medical care (**IV**). This respect for the partner's need for independence in the pre-hospital phase as a possible reason for delay has not been described previously in the literature. Nevertheless, valuable time is lost when people engage in self-treatment, the importance of which in the pre-hospital phase of MI, has been supported by others<sup>98, 107, 116, 120</sup>. One explanation among the elderly patients having confidence in self-care could be that they are used to try different self-care strategies in dealing with chronic illness, which had earlier led to self-reliance and regulation of symptoms<sup>161, 162</sup>. However, we found that patients

with unbearable pain, interpreting the symptoms as cardiac in origin, had a shorter decision-making process compared to those who not taking the symptoms seriously (**I, II**). Like Finnegan et al.<sup>163</sup>, we found that increased severity or constancy of symptoms led most of the patients to re-evaluate the situation, which appeared to form the basis for the final decision to seek care (**III**).

## **Factors influencing the pre-hospital phase**

The patient decision time in Sweden prior to the commencement of our studies was approximately three hours, which seems to be comparable to delay times in other countries<sup>73-78</sup>. Our studies support that patients need sufficient time to recognise the full range of symptoms they experience, as only a quarter of the patients considered going to hospital immediately when feeling the initial symptoms and 59% delayed more than one hour (**I**).

The women with MI had a prolonged decision making process compared with the men (**II**), and this is consistent with earlier studies<sup>96, 101, 164</sup>. Douglas suggest<sup>165</sup> that this may be related to conceptions about the lack of prevalence of CAD in women, by both physicians and patients. Women have also been found to be more likely than men to engage in self-care strategies, contributing to delay<sup>102, 166</sup>. Another explanation for delay among the female MI population, could be that women prioritise their families and household obligations before their own health<sup>154</sup>. These social concerns have also been reported previously in women with an ongoing MI<sup>102, 111, 129</sup>.

An initial contact with the GP before going to hospital turned out to be a critical factor for late presentation in our studies (**I-IV**) and one third of the patients made such a contact (**I**). It is however important to elucidate that it was not the contact with the GP him/herself causing delay; instead it was the patients' and spouses' misconception that the GP represented the correct level of care when experience chest pain, contributing to an unnecessary time delay before coming in contact with the hospital (**III, IV**). This incorrect behaviour by the patients with MI in causing delay, is supported by others<sup>120, 167, 168</sup>. The decision to consult others may be especially appropriate for women who may face considerable uncertainty when confronted by cardiac symptoms<sup>123</sup>. Also the spouses' need for advice and support from others was apparent among some of those in our study who based their actions on GP consultation (**IV**).

A recently published study by Moser and colleagues<sup>129</sup> indicated that experiences of a previous MI do not always result in a decreased pre-hospital decision time, and nor could we find any such relationship (**I, II**). It is disappointing that patients with previous experience of MI do not have shorter decision times. One would expect that prior knowledge and experiences would enhance the patients' responsiveness to MI symptoms, but instead there seems to be other factors, such as denial, that are important. However, absence of strong emotional responses were evident in those patients in our study who had previously experienced a MI; they expressed instead how they felt calm and almost took it for granted that they would get well again (**III**). This could be one explanation why so many MI patients delay when they experience MI symptoms a second time.

Although patients' symptoms generally seemed to be severe, our findings indicate that MI is often not recognisable, at least initially, to spouses because the affected partners keep the symptoms to themselves (**IV**). Patients did not reveal how severe the pain was and did not complain about symptoms; describing instead how they ignored symptoms, because they felt their responsibilities to their family could not be delegated to anyone else (**III**). This finding of over-protectiveness of the family is in accordance with those of Dracup et al.<sup>118</sup>, who found that MI patients are worried about troubling their spouses, thereby prolonging the pre-hospital phase. However, the spouses in study **IV** narrated about how they thus could feel like outsiders, when initially being unable to share the course of events with their partner and how they would like to be involved in the decision making process. This paradox, when couples try to protect each other from their conceptions and emotions, adds to the delay, and an awareness of these common reactions to symptoms is needed among individuals at risk of having an MI. However, whilst concerns for the family prevented some patients in our study (**III**) from seeking medical care, others saw it as natural to tell the spouse about what was happening and involved them in the decision making process. Earlier studies<sup>169, 170</sup> have found that married men tend to rely on their spouses for lay consultation, while married women frequently consult a wider range of both family and friends, but this pattern of differences between the genders was not prominent in our studies (**I-II**).

The spouses tried to attain a kind of distance to the situation, by restraining from revealing their own emotions and seeking agreement with the affected partner as to what actions to perform, waiting for the partner to accept a medical consultation or to call for an ambulance (**IV**). Billings and Moose<sup>171</sup> argue that this so-called emotionally-focused way of coping with an acute event is needed in order to have

the energy to handle the difficulties. When restraining their own emotions, the spouses thought that they protected their partners from becoming upset and thus from worsened symptoms (**IV**). If they had, however, shown their anger and irritation over the partner's irrational behaviour, the decision time might have been decreased. However, the spouses also expressed an ability to become resourceful in this serious situation and solve the problems by taking different alternatives of actions into account; relying on previous knowledge or trying to learn more about the situation by talking to someone competent (**IV**). This can be considered as a problem-focused way of coping with the situation <sup>171</sup>, which has been demonstrated to be an important strategy for decreasing decision times in MI patients <sup>172</sup>. The choice of coping strategy is, however, dependent on how acute the situation is interpreted to be, and strategies are usually used in combination <sup>171, 173</sup>.

The patients expressed how the spouse created a sense of security by showing commitment and infusing courage into them in this serious situation and exemplified practical support as the spouses called the emergency number (**III**), which 40% of the spouses did (**II**). It was also the spouse the patients with suspected MI most often contacted initially when first experiencing the symptoms (**I**). This finding indicates the very important role of a spouse in the decision making process, and has been confirmed by others <sup>105, 123, 174</sup>. The REACT researchers also found that people called for an ambulance for others, but delayed in calling for their own MI symptoms <sup>175</sup>. However, we found an underutilisation of the EMT services with a large proportion of patients with MI symptoms refraining from calling the emergency number as recommended (**I-IV**) and by doing so, they deprive themselves from life-saving treatment in the event of cardiac arrest, as well as delaying the time to reperfusion in the presence of a coronary occlusion. The most frequent reason for non-utilisation of the EMT services turned out to be that the patients did not interpret their symptoms as severe enough to merit a drastic action like calling the EMT services (**II, III**). In accordance with this, the privately transported patients had milder symptoms with smaller myocardial damage than their ambulance-transported counterparts, as judged by objective method (ECG) and their own pain scores (**II**). This indicates that, in spite of the under-utilisation of the EMT, it seems that the patients in the greatest need of pre-hospital treatment actually called for an ambulance, which has been shown before <sup>134</sup>. Earlier research has also found that ambulance users are more often women <sup>132</sup>, and older individuals <sup>133, 176, 177</sup>. Neither gender nor age was, however, shown to predict ambulance use in our study (**II**). The non-ambulance users also perceived the ambulance merely as a means of transport, thereby

choosing self-transportation in the belief that they would be treated faster that way (III). This lack of knowledge about the competence of the ambulance staff has been shown previously<sup>136, 137, 178</sup>, but needs to be highlighted again and addressed in conversation with the patients.

## DISCUSSION OF METHODS

### Design and research approaches

Using both quantitative and qualitative methods was seen as necessary to reach a maximum of different angles of the experiences of the patients' and spouses' in the pre-hospital phase, and to increase the understanding of the complex phenomenon studied in this thesis. Rather than thinking of qualitative and quantitative strategies as incompatible, they should be seen as complementary. When quantitative and qualitative approaches are combined, the methods are often applied in sequential order<sup>179</sup>. Semi-structured interviews might, for example, be used to explore hypothesis or variables when planning a survey study, resulting in e.g. enhanced sensitivity and accuracy of the survey questions. However, qualitative studies can also be added to quantitative ones, to gain a better understanding of the meaning and the implications of the findings<sup>180</sup>, which was the approach in this thesis. A qualitative analysis can also be seen as a final achievement in itself, which does not necessarily have to be examined by further measurement<sup>141</sup>.

### Data collection

#### The quantitative studies

Validity in quantitative research shows the degree to which the instrument measures what it is intended to measure, whereas reliability involves the degree of consistency or dependability with which an instrument measures the characteristics it is designed to measure<sup>143</sup>. The questionnaire used in studies **I** and **II** might have needed some additional testing with regard to validity and reliability. However, since the instrument does not measure a single concept, testing of internal consistency with Cronbach's alpha was not appropriate. The original questionnaire was the only established instrument regarding patients' pre-hospital action available in Swedish at the time of the study, which made its comparison with others impossible.

The patients' experiences were elicited within 48 hours after admittance to the CCU, with a possibility of recall bias the more time that had passed from onset of symptoms. Subjects were also recruited in CCU once pain free and haemodynamically stable. Therefore patients who had ongoing symptoms were excluded. It is possible that these patients were different in terms of delays, thereby introducing selection bias (**I**, **II**). We studied patients' decision time (with a

definition for delay as > 1 hour) (I), excluding the transportation time, which can make the results difficult to compare to others. This interval has, however, recently been used in one other study<sup>121</sup>. It is also a well known practical experience that patients may have difficulties in remembering the exact time when first experiencing symptoms, with a risk for uncertainty regarding the calculated time for onset of symptom made by the patients. Our patients were however carefully instructed in being as exactly as possible when calculating the time. Limitations also include the risk of a selected population, due to the fact that the study only included patients admitted to the CCU (I, II), leaving out the very oldest individuals and those suffering from multiple diseases, since those people were treated at other departments. This is anyhow a consecutive series and can thus be regarded as being representative of the CCU population. Additionally, in relatively small sample sizes, such as in study II, the lack of statistically significant differences between groups may be the result of a lack of statistical power rather than a true lack of effect. This may explain the few statistically significant differences that were noted between ambulance callers and non-users.

### **The qualitative studies**

Sjöström and Dahlgren<sup>141</sup> argued that phenomenography could be applicable for research in the context of health-care, for example when studying understanding of patients' ways of experiencing their disease, its origin, symptoms and treatment. This makes phenomenography applicable to the phenomena explored in studies III and IV. An alternative approach could possibly have been phenomenology. However, although phenomenography and phenomenology have much in common, one of the main differences is that phenomenology searches for the lowest common denominator as the essence whereas phenomenography is substance oriented and searches for the underlying structure of variance as the essence<sup>148</sup>. The phenomenographic approach was also relevant since decision-making, which is a part of the pre-hospital phase, has demonstrated large variations in experience<sup>181, 182</sup>. The variations of conceptions are, however, restricted, which means that the variation is not endless<sup>141</sup>. Therefore, the number of persons selected in studies III and IV was regarded as sufficient. The material consisted of 388 double-spaced pages, which must be seen as a satisfactory amount of data. However, if more respondents had been interviewed, an even larger range of categories could have emerged, but with more data there is always a risk that the analysis becomes superficial, which would undermine the aim of the work<sup>149</sup>. The majority of conceptions in study III emerged within the first eight interviews, with

no new conceptions in the last three interviews. Similarly in study **IV**, after 12 of the 15 interviews, no new conceptions emerged. This indicates that the content covered the issue under investigation.

Several considerations were made to increase the credibility of studies **III** and **IV**. Strategic theoretical sampling was performed in a stepwise way to achieve variation in important variables, as suggested by Polit & Beck<sup>143</sup> and Kuzel<sup>183</sup>. Tape recordings were used to obtain data, which is considered important when studying active understanding among patients<sup>184</sup>. In phenomenography, a semi-structured interview is most often the method of generating data<sup>182</sup>. This method requires the interviewer to immediately interpret the respondents' answer to be able to decide about further questioning<sup>141</sup>. Our interview guide was rather open, with just one opening question, which enhanced the possibility of using probes. In addition, all interviews were concluded with a follow-up question, which gave the informant an opportunity to raise questions that had not come up during the interview or that he/she had not thought about previously. Presentations of contextual backgrounds in the different materials, such as demographics and study setting, were made for the reader to be able to determine in which situations the findings might provide valid information and if they could be applied in a similar setting. The differences and similarities described by the respondents were exemplified by providing original quotations from the interviews to support the relevance of the categories. The concept of reliability in phenomenographic research is sometimes discussed in terms of whether another researcher can identify the different categories in the interview data<sup>145</sup>; and in both qualitative studies (**III**, **IV**), a satisfactory inter-rater reliability was reached. An additional aspect is whether another researcher would suggest the same categories after having worked with the same material, but this was not done in our studies since Marton<sup>145</sup> holds the view that this demand for replicability is not justified, or even desirable. Rather, the actual identification and description of the categories constitutes the "discovery" of the study.

## **Generalisability**

We used both quantitative and qualitative methods, to secure an in-depth understanding of the phenomenon in focus: The MI patients' and spouses' experiences of the pre-hospital phase. The use of the consecutive sample of CCU patients with chest pain (**I**, **II**), as well as the strategic sample of MI patients and their spouses at the CCU (**III**, **IV**), probably make the findings representative for other CCU patients and their spouses in a Swedish population.



## CONCLUSIONS

- The majority of patients suspected that their symptoms emanated from the heart, but despite this, nearly two thirds delayed going to hospital by > 1 hour after onset of symptoms, and the patient's subjective feeling of the severity of symptoms was an important predictor for delay times **(I)**
- It was a common strategy for the patients to consult his/her spouse and/or the general practitioner early in the pre-hospital phase when experiencing some kind of discomfort from the chest. The decision to contact the general practitioner was however associated with a prolonged pre-hospital phase **(I)**
- There is still ambulance under-utilisation among patients with acute MI, with patients perceiving the ambulance merely as an option for transportation to hospital if they have unbearable symptoms. However, those patients in the greatest need of pre-hospital care, the STEMI patients, went by ambulance more frequently compared with the NSTEMI patients. Nevertheless, it was usually the spouse who called the emergency number, and not the patient him/her self **(II)**
- Cognitive and emotional responses were important in the patients' decision-making about responding to the symptoms of a possible evolving MI. The patients' conceptions about manageability, vulnerability and interaction with others emphasised the great complexity of this phenomenon **(III)**
- Spouses seemed to have a strong effect on the course of events and played a considerable role in the decision-making process; revealing that the spouses were resourceful as well as respected their partners' need for independence in the pre-hospital phase **(IV)**



## CLINICAL IMPLICATIONS

The role of healthcare professionals in educating their patients to recognise and respond to possible cardiac symptoms as rapidly as possible is essential in order to improve survival rates in patients with acute MI. However, symptom interpretation and management is a complex phenomenon, and a deeper understanding from the patients' and spouses' perspectives is needed when designing different educational interventions. It would seem to be clear that the focus of educational interventions should shift in emphasis from public toward individual education for a number of reasons, the primary reason being that it is then possible to individualise the message. Hence, the results from this study could be used as a part in the individual education of the patient and the spouse, in the primary as well as in the secondary care settings.

### **Primary preventive education**

It is important that prior to an event, physicians and nurses in the primary healthcare setting, modify the education to suit persons who may have difficulties with symptom identification and those at high risk of developing an acute MI; such as those with hypertension, angina or diabetes, and who visit their doctor or nurse on a regular basis at the GP's office. Tailored educational strategies, designed to address these populations, could be more successful in reducing delay when falling ill with an acute MI in the future, since the individuals identify with the material they are reading or hearing about. Firstly, the majority of educational materials of today focus on chest pain; when atypical symptoms, mild chest discomfort and associated symptoms must also be presented and discussed as important signs of MI. Secondly, a development of tailored individual material should also contain information about the high-risk patients' risk of having an MI in the future. Thirdly, a discussion must be commenced about common behavioural patterns; such as a desire to deny the severity of symptoms and trying different self-care strategies adds to delay and is misleading, although the denying mechanisms probably are difficult to reach with education. However, it is important to point out that these primary preventive intentions to reduce patient delay may cause unnecessary worries in some individuals that considered themselves as healthy persons.

## **Secondary preventive education**

In order to shorten the pre-hospital phase in a possible recurrent MI, it is important to identify the MI patients at the CCU who contacted the GP instead of immediately seeking hospital admittance. These patients should be educated about the disadvantageous delay times when they first contact the GP instead of calling for an ambulance at once. Additionally, not considering one-self sick enough to require ambulance transportation, or not being aware of the competence the paramedics possess, implies an unnecessary suffering for the MI patient. This attitude needs to be adjusted in the education of the non-ambulance users, since death and disability can be greatly reduced if patients are motivated to call the EMT services.

Given the role spouses play in the decision-making process, the early in-hospital education should be undertaken together with the spouses in order to assist the partners in making timely decisions related to future MI symptoms. However, the educational needs of patients and spouses may be different, which is why it may be important to produce separate verbal, as well as written, information material. This material should focus on the spouses' own behaviours and give examples of common reactions. Due to their short hospital stays, patients may still be in a state of shock, making them less receptive to information; hence, the education of the MI patients and their spouses regarding proper pre-hospital behaviour should be repeated during the multidisciplinary rehabilitation programme. The healthcare professionals should use the individual's own conceptions of his/her illness as a starting-point for discussion of possible future cardiac events and build the education around these existing conceptions. However, the intervention needs to be followed up continuously in terms of patient delay-times and utilisation of the ambulance services.

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## APPENDIX A

## Patienters agerande i samband med misstänkt hjärtinfarkt - patient delen

## Symtomen (fråga 1-9)

1. Vad var det för *symtom* som gjorde att Du uppsökte sjukvård nu?

Bröstmärta:

Obehag eller tryck från bröstet:

Smärta i armar, hals eller käke:

Trötthet, svaghet:

Andnöd:

Yrsel eller svimningskänsla:

Illamående, kallsvett:

Ångest, rädsla:

Allmän sjukdomskänsla:

Annat:  vad? \_\_\_\_\_

2. Om Du upplevde *smärta, tryck* eller *obehag*, hur vill Du beskriva dess karaktär?

Åtstramande:

Knivskarp:

Tryckande:

Molande:

Brännande:

Ömmande:

Svidande:

Huggande:

Krampande:

Annat:  vad?: \_\_\_\_\_

3. Om Du fick gradera den *maximala smärtan, trycket* eller *obehaget* Du kände i anslutning till insjuknandet på en skala från 0 till 10, där 0 betyder smärtfri och 10 den värsta tänkbara smärta Du kan tänka Dig, vilken siffra skulle Du då ange?:

(smärtfri) (0)  (1)  (2)  (3)  (4)  (5)  (6)  (7)  (8)  (9)  (10)  (max smärta)

4. Hur *upplevde* Du Dina symtom?

Irriterande:

Besvärliga:

Outhärdliga:

Kvävande:

Stressande:

Obehagliga:

Ångestfyllda:

Annat:

vad?: \_\_\_\_\_

5. Har Du *haft attacker* med liknande besvär *före* det aktuella insjuknandet?

Ja:  Om Ja, besvara frågorna (a-f) nedan.

Nej:  Om Nej, gå direkt till fråga 6.

a) Under hur lång tid före insjuknandet har Du haft dessa attacker?

Mindre än en vecka:  1-2 veckor:  3-4 veckor:  1-2 mån:  Mer än 2 mån:

b) Hur ofta kommer attackerna?

Flera attacker / dag:  En attack / dag:  3-6 attacker / vecka:  Färre än 3 attacker / vecka:

c) Hur länge varar attackerna?

Mindre än 5 min:  5-10 min:  10-15 min:  Mer än 15 min:

d) Har attackerna kommit *oftare* den senaste tiden? Ja:  Nej:

e) Har attackerna ändrats så att de *varat längre* varje gång? Ja:  Nej:

f) Har attackerna ändrats så att de är *mer intensiva*? Ja:  Nej:

6. Var trodde Du att de *symtom* som gjorde att Du uppsökte sjukvård, *härörde ifrån*?

a) Hjärtat:  *Om hjärtat*, markera med kryss och gå sedan till fråga (7).

b) Övrigt, varifrån?:  *Markera* något av *alternativen nedan* och gå sedan till fråga (8).

Musklerna:  Lungorna:  Gallblåsan:  Tänderna/käken:

Magen:  Ryggen:  Vanlig förkylning:  Annat:  vad?: \_\_\_\_\_

7. Om Du *misstänkte* att Dina *symtom* kom från *hjärtat*, vilken var orsaken till denna misstanke?

Har haft hjärtinfarkt tidigare:

Har haft kärlekskramp tidigare:

En vän/granne har haft hjärtinfarkt:

En anhörig har haft hjärtinfarkt:

Har läst i dagstidningarna om hjärtinfarkt:

Erhållit information om hjärtinfarkt via radio eller TV:

Informerad av läkare om symtomen på hjärtinfarkt:

Informerad av sjuksköterska eller annan vårdpersonal om symtomen på hjärtinfarkt:

Annan informationskälla:  vilken?: \_\_\_\_\_

8. Om Du trodde att *symtomen* kom *någon annanstans* än från hjärtat, var Du helt övertygad om att besvären inte hade med hjärtat att göra? Ja:  Nej:

9. *Hur dags* uppstod de första *symtomen* som förde Dig till sjukhus?:

Kl: \_\_\_\_\_ Datum: \_\_\_\_\_ Minns inte klockslaget:

### Händelseförloppet (fråga 10-18)

10. Var *befann Du Dig* när *symtomen* som gjorde att Du uppsökte sjukvård, uppkom?

Ensam hemma:

Hemma tillsammans med någon:

Hos barn, vänner eller släktingar:

På väg till eller från arbetet:

På arbetet:

Ute bland främmande människor:

Ute tillsammans med vänner eller bekanta:

Ute tillsammans med familjemedlemmar:

På annan plats:  vilken?: \_\_\_\_\_

11. Vad *gjorde* Du just innan de *symtom* som gjorde att Du uppsökte sjukhus, började?

Vilade:

Genomförde en måttligt fysisk aktivitet (tex. lugn promenad, hushållsarbete):

Genomförde en kraftig fysisk aktivitet (tex. snabb promenad, gång i trappa):

Var på jobbet och arbetade:  Annat:  vad?: \_\_\_\_\_

12a) Intog Du *någon medicin* för att lindra *symtomen*? Ja:  Nej:

*Om Ja*, vilken (a) *mediciner*?:

Acetylsalicylsyra (magnecyl®, trombyl®):  Andra värktabletter (panodil®, reliv®):

Nitroglycerin:  Andra läkemedel, vilka?: \_\_\_\_\_

b) Gjorde Du *något annat* för att lindra *symtomen*? Ja:  Nej:

*Om Ja*, vad gjorde Du?: \_\_\_\_\_

## 13. Hur reagerade personerna omkring Dig när Du berättade om Dina symtom?

- De sade eller gjorde ingenting:
- De sade åt mig att inte oroa mig:
- De försökte göra det bekvämt för mig:
- De föreslog att jag borde vila:
- De föreslog att jag borde inta någon medicin:
- De föreslog att jag skulle söka sjukvård / ringa 112:
- De ringde 112 åt mig:
- De tog mig till sjukhus:
- De blev upprörda:
- Jag berättade aldrig för någon om mina symtom:

## 14. Vem kontaktade Du först för att fråga om råd?

- |   |  |
|---|--|
| Make/maka: <input type="checkbox"/>                 | Vän eller släkting: <input type="checkbox"/>               |
| Ringde 112 för rådgivning: <input type="checkbox"/> | Ringde 112 för ambulanstransport: <input type="checkbox"/> |
| Min husläkare: <input type="checkbox"/>             | En främling i närheten: <input type="checkbox"/>           |
| Mitt / mina barn: <input type="checkbox"/>          | Kontaktade aldrig någon: <input type="checkbox"/>          |
| Annan person: <input type="checkbox"/>              | vem?: _____  |

## 15. Kontaktade Du vårdcentralen innan transporten till sjukhus?

- Ja, jag ringde till vårdcentralen för rådgivning:
- Ja, jag uppsökte vårdcentralen för rådgivning:
- Nej, jag uppsökte sjukhus direkt:

## 16. Vad tänkte Du när Dina symtom började?

- "Det här är troligtvis inget allvarligt och går nog snart över":
- "Jag måste vara allvarligt sjuk":
- "Jag kommer nog att dö":
- Annat:  vad?: \_\_\_\_\_

## 17. Vad var orsaken för beslutet att uppsöka sjukhus?

- Besvären var så pass svåra:
- Hade inte så ont men kände mig mycket dålig:
- Trodde att jag fått en hjärtinfarkt:
- Trodde att besvären kom från hjärtat:
- Trodde att jag drabbats av en allvarlig sjukdom:
- Blev uppmanad att uppsöka sjukvård av min make/maka:
- Blev uppmanad att uppsöka sjukvård av annan person:
- Annan orsak:  vilken? \_\_\_\_\_

## 18. Tvekade Du att uppsöka sjukhus, vad var i så fall orsaken till detta?

- Tvekade inte:
- Trodde att symtomen skulle gå över:
- Trodde inte att det var något allvarligt:
- Ville inte oroa min familj:
- Ville inte riskera att bli betraktad som inbillningssjuk eller pjoskig:
- Ville inte väcka uppseende inför grannarna:
- Ville inte störa på sjukhuset, inte ställa till besvär:
- Kände obehag inför tanken att bli inlagd på sjukhus:
- Har hört om de långa väntetiderna på akuten och ville inte riskera att behöva vänta i timmar:
- Har hört att det är ont om platser på sjukhuset och ville inte riskera att bli placerad i en korridor:

**Transporten till sjukhus (fråga 19-29)**

19. Hur skedde transporten till sjukhus?

Ambulans:  Taxi:  Buss eller tåg:   
 Körde själv i egen bil:  Blev skjutsad av vän eller släkting:   
 Promenerade:  Annat färdstätt:

20. Om Du åkte ambulans, vem ringde 112?

Jag själv:  Min make/maka:  Mitt barn:   
 En granne:  En arbetskamrat:  Annan person:

21. Har Du åkt ambulans förut, innan Du drabbades av de aktuella symtomen?:

Ja:  Nej:  Om Ja, hur upplevde Du den transporten? Positiv:  Negativ:  Vet ej:

Ev. kommentar \_\_\_\_\_  
 \_\_\_\_\_

22. Om Du kom till sjukhuset på annat sätt än med ambulans, vad var det som avgjorde att Du inte ringde 112 för ambulanstransport till sjukhuset?

Onödigt att beställa ambulans:   
 Finns andra som behöver ambulansen bättre:   
 Trodde jag skulle bli nekad ambulanstransport av SOS-operatören:   
 Tanken föll mig aldrig in att åka ambulans:   
 Visste inte att ambulanspersonalen hade kompetens att starta behandling i hemmet:   
 Enklare att ta taxi eller bli skjutsad:   
 Enklast att köra bil själv:   
 Ville inte besvära:   
 Ville inte väcka uppmärksamhet inför de som befann sig i min närhet, ex. grannar, arbetskamrater:   
 Ansåg mig inte vara tillräckligt svårt sjuk:   
 Mitt färdstätt var snabbare:   
 Annan orsak:  vilken?: \_\_\_\_\_

23. När började Du fundera på att åka till sjukhus?

Omedelbart när jag kände de första symtomen:   
 När symtomen inte ville gå över:   
 När symtomen förvärrades:   
 När jag blev uppmanad av någon att åka:   
 Annan orsak:  vad? \_\_\_\_\_

24. Hur länge hade Du känt av Dina symtom innan Du beslutade Dig för att uppsöka sjukvård, dvs. ringde 112 alt. begav Dig till sjukhuset?:

< 15 min:  15-30 min:  30-60 min:  1-2 tim:  > 2 tim:

25. När Du väl beslutat Dig för att åka till sjukhus, när kom Du iväg?

Utan dröjsmål:  Efter ett visst dröjsmål:   
 Efter ett ganska långt dröjsmål:  Efter ett mycket långt dröjsmål:

26. Om *Du dröjde*, vad berodde dröjsmålet på?

Ingen telefon tillgänglig:

Ville prata med anhöriga först:

Ville klä på mig först:

Ville packa en väska först:

Ville ordna med en del saker först (tex. diska, plocka undan, vattna blommor):

Ville ordna en del ärenden först (tex. viktiga papper, avboka åtaganden, bank- eller postärenden):

Provade med någon form av egenvård, såsom intog mediciner eller vilade, först:

Visste inte att det var så viktigt att så tidigt som möjligt åka till sjukhus:

Ingen ledig ambulans tillgänglig:

Det fanns ingen som kunde skjutsa mig till sjukhuset:

Annan orsak:  vilken?: \_\_\_\_\_

27. Tidpunkt för *beslut* att åka till sjukhus:

Kl: \_\_\_\_\_

Datum: \_\_\_\_\_

Minns inte klockslaget:

28. Tidpunkt då *resan* till sjukhuset började:

Kl: \_\_\_\_\_

Datum: \_\_\_\_\_

Minns inte klockslaget:

29. Har Du någonsin *hört talas om* ett läkemedel som ibland används på sjukhus för att stoppa utvecklingen av en hjärtinfarkt? Läkemedlet kallas trombolys eller "propplösare".

Ja:

Nej:

Om *Ja*, hur har du hört talas om detta läkemedel?:

Har själv erhållit trombolys tidigare:

En anhörig eller bekant har berättat för mig om trombolys:

Har läst en artikel i en dagstidning:

Har hört ett inslag på radio:

Har sett ett inslag på TV:

Har erhållit information via Internet:

Har erhållit information på apoteket:

Har erhållit information via läkare:

Har erhållit information via sjuksköterska eller annan vårdpersonal:

Annan informationskälla:  vilken?: \_\_\_\_\_

**Allmänna frågor (fråga 30-38)**30. Kön: Man:  Kvinna: 

31. Födelseår: \_\_\_\_\_

32. Nationalitet: Svensk:  Annan nationalitet:  vilken?: \_\_\_\_\_

33. Tidigare medicinska data:

a) Är Du rökare?: Ja:  Nej: b) Behandlas Du för högt blodtryck?: Ja:  Nej: c) Har Du diabetes?: Ja:  Nej: d) Har Du kärlkramp?: Ja:  Nej: e) Har Du haft hjärtinfarkt tidigare?: Ja:  Nej: *Om Ja:*En tidigare infarkt:  Två tidigare infarkter:  Fler än två tidigare infarkter: f) Annan allvarlig sjukdom?: Ja:  Nej:  *Om Ja, vilken:* \_\_\_\_\_34. Aktuellt civilstånd: Ensamboende:  Sammanboende: 35. Bostad: Hyreslägenhet:  Bostadsrätt:  Villa: a) *Om Du bor i villa, hur långt har Du till närmaste granne?*Inom 500 meter:  500-1000 meter:  Längre än 1 km: 36. Hur *långt* hade Du uppskattningsvis till närmaste sjukhus, då Du insjuknade?≤ 1km:  1-5km:  6-10km:  > 10km: 37. Var Du i *fullt arbete* då Du blev sjuk?a) Ja:  Nej: *Om Nej, är Du:* Sjukskriven:  Sjukpensionär:  Ålderspensionär: Studande:  Arbetslös: b) Vad har/hade Du för *yrke*? \_\_\_\_\_38. Utbildning: Folkskola/Grundskola:  Gymnasieskola/Yrkesskola: Universitet/Högskola:

## APPENDIX B

## Patienters agerande i samband med misstänkt hjärtinfarkt - medicinska delen

## Vårdförlopp (ifylls av ansvarig HIA sjuksköterska)

Åkte pat. ambulans till sjukhuset?: Ja, till akuten:  Ja, till HIA direkt:  Nej:

Tidpunkt då SOS fick larmet<sup>1</sup>: Kl: \_\_\_\_\_ Datum: \_\_\_\_\_

Anlände till pat: Kl: \_\_\_\_\_

Lämnade hämtplats: Kl: \_\_\_\_\_

Avlämnade pat: Kl: \_\_\_\_\_

Tidpunkt då pat. anlände till akuten / alt. HIA direkt: Kl: \_\_\_\_\_ Datum: \_\_\_\_\_

Om patienten kom via akuten, när anlände patienten till HIA?: Kl: \_\_\_\_\_ Datum: \_\_\_\_\_

Vilken diagnos erhöll patienten?:

a) Hjärtinfarkt (STEMI) ST-höjning:  Trombolys?: Ja:  Nej:

Primär PTCA?: Ja:  Nej:

b) Hjärtinfarkt (NSTEMI) icke ST-höjning:

c) Angina pectoris:  Instabil?: Ja:  Nej:  Vet ej:

d) Icke hjärtinfarkt / obs bröstsmärta:

Hjärtinfarktens lokalisation:

Anterior:  Lateral:  Inferior:  Generell:  Övrigt / obestämbart:

Infarktskademarkörer (maxvärde):

Troponin-T: \_\_\_\_\_ Myoglobin: \_\_\_\_\_ CK-MB: \_\_\_\_\_

Deltar patienten i någon trombolysstudie?: Ja:  Nej:

Har pat. accepterat deltagande i studien?: Ja:  Nej:

Formuläret ifyllt av: \_\_\_\_\_

<sup>1</sup> Uppgifterna hämtas från ambulansjournalen.



## APPENDIX C

**Patienters agerande i samband med misstänkt hjärtinfarkt  
Telefonuppföljning 1 år**

Inläggningsdatum: \_\_\_\_\_ Inkom med ambulans: Ja:  Nej:

Uppföljningsdatum: \_\_\_\_\_ Journal:  Telefon:

**Deltagarstatus:**

Medverkar:  Avböjer:  Ej anträffbar:

Avliden:  a) Kardiovaskulär händelse:  b) Annan händelse:

**Uppföljning:**

1. Kommer Du ihåg att Du fyllde i en *enkät* på Hjärtintensiven för ca ett år sedan angående vad Du gjorde innan du sökte sjukvård för bröstsmärtor?  
Ja:  Nej:

2. Har Du varit *inlagd på sjukhus* sedan den aktuella sjukhusvistelsen?:  
Ja:  Nej:

Om Ja;

a) Orsak?: Obs. bröstsmärta:  antal ggr: \_\_\_\_\_ ambulans: Ja:  Nej:   
 Angina:  antal ggr: \_\_\_\_\_ ambulans: Ja:  Nej:   
 Hjärtinfarkt:  antal ggr: \_\_\_\_\_ ambulans: Ja:  Nej:   
 Annan orsak:  antal ggr: \_\_\_\_\_ ambulans: Ja:  Nej:

b) Om Du åkte ambulans; vem ringde 112?

Jag själv:  Annan person:  vem?: \_\_\_\_\_

c) Om Du varit inlagd fler gånger; Har *enkäten i sig* lett till att Du funderat över Dina handlingar i samband med insjuknandet, och förändrat Ditt agerande vid de andra inläggningarna?  
Ja:  Nej:

Ev. kommentar:

---

d) Revaskulariserad?: Ja:  PCI:  CABG:  Nej:

Signatur ssk: \_\_\_\_\_