Coronary Heart Disease and Early Decision Making, from Symptoms to Seeking Care

Studies with Focus on Pre-hospital Delay in Acute Myocardial Infarction Patients

CATRIN HENRIKSSON
Dissertation presented at Uppsala University to be publicly examined in Enghoffsalen, Akademiska sjukhuset, Uppsala. Friday, September 16, 2011 at 13:00 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish.

Abstract

Despite several investigations and interventions aimed at decreasing the time from symptom onset to medical care seeking in acute myocardial infarction patients, the delay time is still too long for best treatment outcomes. In this thesis, investigations aimed at improving our understanding of the factors influencing delay time are evaluated, as well as attitudes to medical care seeking in patients, relatives and the general public. Additionally, an evaluation was performed to examine whether health-related quality of life had any influence on delay time and re-admissions.

Participating patients, relatives and representatives of the general public were generally knowledgeable about acute myocardial infarction (AMI) and its symptomatology. The majority of participants knew about the importance of receiving fast treatment when an AMI occurs. Despite people’s knowledge, several patients and relatives felt uncertain of symptom origin and how to act at symptom onset. Patients commonly consulted an additional person when symptoms did not disappear. However, people appeared to act more appropriately if someone else had chest pain compared to self-experienced symptoms.

In patients who had suffered from more than one AMI, poor total health status increased the risk of delaying for more than two hours, but no independent association was found between total health status and re-admissions within the first year post-AMI.

Keywords: Acute Myocardial Infarction, Pre-Hospital Delay, Knowledge, Attitudes, Decision Making, Quality of Life, Re-admission

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ISSN 1651-6206 0346-5462
ISBN 978-91-554-8114-8
urn:nbn:se:uu:diva-156636 (http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-156636)
You may delay but time will not.

*Benjamin Franklin*
List of Papers

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


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### Abbreviations

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<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>ACC</td>
<td>American College of Cardiology</td>
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<td>ACS</td>
<td>Acute Coronary Syndrome</td>
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<tr>
<td>AHA</td>
<td>American Heart Association</td>
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<td>AMI</td>
<td>Acute Myocardial Infarction</td>
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<tr>
<td>CABG</td>
<td>Coronary Artery Bypass Grafting</td>
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<tr>
<td>CCU</td>
<td>Coronary Care Unit</td>
</tr>
<tr>
<td>CHD</td>
<td>Coronary Heart Disease</td>
</tr>
<tr>
<td>ECG</td>
<td>Electrocardiogram</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency Department</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>EuroQol-5 dimension (Questionnaire about health-related quality of life)</td>
</tr>
<tr>
<td>ICCU</td>
<td>Intensive Cardiac Care Unit</td>
</tr>
<tr>
<td>LBBB</td>
<td>Left Bundle Branch Block</td>
</tr>
<tr>
<td>MI</td>
<td>Myocardial Infarction</td>
</tr>
<tr>
<td>NSTEMI</td>
<td>Non ST-segment Elevation Myocardial Infarction</td>
</tr>
<tr>
<td>PCI</td>
<td>Percutaneous Coronary Intervention</td>
</tr>
<tr>
<td>RIKS-HIA</td>
<td>Register of Information and Knowledge about Swedish Heart Intensive Care Admissions</td>
</tr>
<tr>
<td>SAS</td>
<td>Statistical Analysis System</td>
</tr>
<tr>
<td>SEPHIA</td>
<td>Secondary Prevention after Heart Intensive Care Admission</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for Social Sciences</td>
</tr>
<tr>
<td>STEMI</td>
<td>ST-segment Elevation Myocardial Infarction</td>
</tr>
<tr>
<td>UCR</td>
<td>Uppsala Clinical Research Center</td>
</tr>
<tr>
<td>VAS</td>
<td>Visual Analogue Scale</td>
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INTRODUCTION

In Europe approximately 40% of all mortality in people <75 years old is caused by cardiovascular disease. The majority of deaths from coronary heart disease (CHD) occur before the patient reaches hospital after symptom onset. Swedish data on pre-hospital mortality is shown in Figure 1. The first manifestation of CHD is often sudden death, and of those patients 20% had no prior heart disease. The most critical period in case of an AMI is the first 1-2 hours after symptom onset, and many serious events are correlated to severe arrhythmias. Early thrombolytic treatment or acute Percutaneous Coronary Intervention (PCI) are determining factors for prognosis and survival in ST-elevation myocardial infarction (STEMI) patients. Reperfusion treatment given within 90 minutes (from medical care arrival to start of treatment) will salvage about half of the myocardium and limit the risk of cardiac complications. However, to have the opportunity to receive the best treatment result, patients have to seek medical care more rapidly. Pre-hospital and immediate in-hospital diagnosis and treatment have improved over time, but the patients’ decision-time is unchanged. Campaigns aimed to decrease patients’ delay time have often failed to show long term results.
Figure 1. The relative proportion of pre-hospital mortality in Swedish AMI patients has increased over the last 20 years in Sweden\textsuperscript{17}.

Acute Myocardial Infarction

AMI is defined as myocardial cell necrosis caused by ischemia.

Clinical criteria for the diagnosis of AMI:
1. Cardiac biomarkers (Troponin, CK-MB) with typical rise and gradual fall, and/or:
2a. ischemic symptoms
2b. ECG changes indicative of new ischemia (new ST changes, including ST-segment elevation or depression, T-wave abnormalities or development of new pathological Q-wave or new left bundle branch block (LBBB)).
2c. imaging evidence of new loss of myocardium or new regional wall motion abnormality\textsuperscript{18}.

Acute Myocardial Infarction is often divided into ST-segment elevation myocardial infarction (STEMI) and non-ST segment elevation myocardial
infarction (NSTEMI). When a sudden occlusion of a coronary artery occurs, the ECG usually shows ST-segment elevations, or less often, left bundle branch block (LBBB). Myocardial necrosis starts to develop after 15 minutes of ischemia \(^9,19\). In NSTEMI cases, ECG commonly shows ST-segment depression and/or T-wave inversion or sometimes no ECG changes at all. In this type of myocardial infarction there is only a partial occlusion of the coronary artery \(^18,20\).

**AMI-symptoms**

Pain, pressure, discomfort in the chest, lasting for more than 20 minutes, are the most common symptoms of AMI \(^19,21\). Some patients experience typical symptoms, and some have no symptoms at all \(^4\). Less than half of the AMI patients experience sudden symptom onset \(^22,23\), and there are often differences in people’s expected and experienced symptoms \(^21,24,25\), see Figure 2. Female patients more commonly report symptoms such as back pain and nausea \(^22,26\), and elderly patients indicate more gradually increased pain and vaguer symptoms \(^22,27\) than younger ones.

![Figure 2. Expected and experienced symptoms in relation to an AMI. Data extracted from Horne R (2000) \(^21\).](image)
Delay time

The total delay time is commonly divided into three phases:

1. Patient decision time
2. Transportation time
3. Hospital delay time (physician’s decision time) 28-30

1. Patient decision time is defined as the time from symptom onset to seeking medical attention. During this phase, patients have to interpret the symptoms as serious or not. Both patients and the people around them affect behaviours contributing to the decision time.

2. Transportation time is the interval from calling the alarm number to hospital arrival, or in cases of private transportation, the time is estimated from the decision to seek medical care to arrival at the hospital.

3. Hospital delay time is the time between hospital arrival (or other treating units) and start of treatment (in case of STEMI, start of reperfusion treatment).

The definition of pre-hospital delay time is “the time from onset of symptoms until hospital arrival”. The major part of the total pre-hospital delay time is related to the patient 30, see Figure 3.

Figure 3. Distribution of the total delay time.
Data extracted from Weaver WD (1995) 31.
According to the American College of Cardiology/American Heart Association Guidelines (ACC/AHA) 4, STEMI patients should be treated within 120 minutes from symptom onset to initiation of reperfusion treatment. In Sweden, as in other countries 12,32,33, the time from symptom onset to arriving at the Emergency Department is about two hours. This has not changed over the years 12,13, see Figure 4.

**Figure 4.** Delay time in AMI patients, RIKS-HIA, 1995-2009. Data from the national register RIKS-HIA.

### Factors associated with patient delay

In several studies female gender, older age, diabetes, prior angina and hypertension are related to prolonged decision time 23,28,30,34. Even those patients with prior AMI do not have shorter delay time 23,28. Symptom presentation commonly influences the decision time: severe symptoms sudden onset and haemodynamic instability 23,35,36 often lead to faster action. Milder symptoms, especially in cases of gradually onset, as well as intermittent symptoms prolong the decision time 28,37,38. Other factors causing delay are patients’ interpretation of their symptoms as a non-serious condition 39,40, and uncertainty about which symptoms to react
However, people’s expectations do not always match symptom experience and misinterpreting of symptoms is common in AMI patients. A common false conception is that an AMI always has a sudden onset with severe chest pain. Onset of symptoms at home and being alone at symptom onset also increases the delay time.

Patients often delay because they expect the pain to disappear and wait for this to happen. Trying self-treatment such as taking pain-killers or antacids or relaxing also increases the delay time. Those patients who do not want to trouble or worry others about their illness, and those who consult with others before medical professionals often have prolonged delay time. Contacting a spouse or another family member increases the delay time further, compared to consulting a lay person.

Individuals who not perceive themselves as vulnerable to coronary heart disease delay for an even longer time. People often try to reject unpleasant feelings and denial of symptoms is a common reaction post-AMI, which increases the decision time before seeking medical care.

A summary of factors affecting delay time is shown in Figure 5.

**Figure 5.** Factors influencing the delay time in AMI patients.

<table>
<thead>
<tr>
<th>Increasing delay</th>
<th>Decreasing delay</th>
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<tr>
<td>Older age</td>
<td>Severe symptoms with abrupt onset</td>
</tr>
<tr>
<td>Female gender</td>
<td>Wide range of symptoms</td>
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<tr>
<td>Diabetes</td>
<td>Haemodynamic instability</td>
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<td>Hypertension</td>
<td>STEMI</td>
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<tr>
<td>Heart failure</td>
<td>Syncope/shock</td>
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<tr>
<td>Hyperlipidaemia</td>
<td>Interpret symptoms as cardiac</td>
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<tr>
<td>Depression</td>
<td>Consultation with a non-family member</td>
</tr>
<tr>
<td>Symptom expectation does not match experienced symptoms</td>
<td>Knowledge of seriousness of symptoms and the importance of seeking medical care quickly</td>
</tr>
<tr>
<td>Consultation with a family member</td>
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<tr>
<td>Denial</td>
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Knowledge of AMI and the medical care seeking process

Studies have shown that people in general are well aware that chest pain and radiating pain in the left arm are symptoms of an AMI, but they often fail to recognise other symptoms. Patients who are well-informed about potential AMI-symptoms and who know about a wide range of symptoms often delay for a shorter time. Awareness about the importance of receiving rapid treatment decreases the delay time.

Descriptions of attitudes and behaviour

*Attitude* is described as a learned implicit anticipatory response gained from experience. Attitude is a disposition to respond favourably or unfavourably to an object, person, institution or event. Attitudes are hypothetical constructs that, being inaccessible to direct observation, must be inferred from measurable responses.

*Behaviour* is described as a product of an individual’s learning history, their present perceptions of the environment and intellectual and physical capacities. Behaviour can be changed through new learning experiences.

Attitudes to medical care seeking

The importance of people’s attitudes to medical care seeking in the case of an AMI is less frequently investigated. It is already known that people’s intention to call the alarm number in case of self-experienced symptoms is high, but they would act faster and more appropriately for others suffering from chest pain. Patients commonly interpret their own symptoms as not being serious enough to call for an ambulance. The proportion of female community members who intend to call the alarm number and immediately go to hospital was high in one study, despite the fact that women are known to delay longer than men.

Psychology

The fact that patients often deny symptoms when an AMI occurs is already well-known. They commonly try to avoid stimuli associated with a prior AMI and the memories influence the person’s degree of psychological defence, and the memories influence the person’s degree of psychological defence.
Some patients believe that an AMI will cause loss of social control and identity, and about 25% of AMI patients experience severe stress disorder, with emotions ranging from anxiety and depression to post-traumatic stress. Long periods of stress might develop both anxiety and depression, and nearly half of all STEMI patients have clinical symptoms of depression. Those emotions increase morbidity and mortality in AMI patients. The ACC/AHA Guidelines recommend an evaluation of AMI patients’ psychosocial status before discharge. In addition, patient education and preferably that of relatives too are known to decrease anxiety.

**Health-Related Quality of Life (HRQL)**

WHO has defined quality of life as "individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment". Patients with a serious disease often experience negative emotions and this correlates to a lower HRQL. Factors such as multiple symptoms, re-infarction, re-admission and co-morbidities are also shown to decrease HRQL. AMI patients are known to have a lower HRQL than the general public.

**Health-Related Quality of Life Measurements (EQ-5D)**

The EuroQol-5 dimension (EQ-5D) instrument is a generic tool measuring health-related quality of life, and was developed by the EuroQoL group. EQ-5D has previously been validated for acute coronary syndrome patients.

Patients estimate their state of health in five dimensions (EQ-index):

- mobility
- self-care
- usual activities
- pain/discomfort
- anxiety/depression

Each dimension is divided into three levels of answers:

- No problems
- Some problems
- Extreme problems
A summary of these dimensions describes the health status as an index, where the maximum health is equal to 1.0.

The patients also estimate their total health status on a self-rating 20-centimeter, vertical scale with the end-points “Best imaginable health state” (100) and “Worst imaginable health state” (0)\textsuperscript{76}.

In the annual report of SEPHIA data (2009)\textsuperscript{79} the EQ-index was on average 0.80 and EQ-VAS was 72 at the one-year follow-up. In a healthy population in Stockholm, the EQ-index was 0.84 for men (median age 65 years) and 0.80 for women (median age 71 years), and EQ-VAS was 77.4 for men and 75.8 for women\textsuperscript{80}. Figure 6 shows the differences between AMI patients and the general population.

However, the reported HRQL in the SEPHIA register\textsuperscript{81} is shown to be stable between the first (6-10 weeks post-AMI) and second (12-14 months post-AMI) follow-up, see Figure 7.

\textbf{Figure 6.} Comparisons in HRQL between AMI patients and a general population. EQ-VAS (mean) at 1\textsuperscript{st} follow-up in SEPHIA 2009 (at least 10 patients in the group), by age and gender, compared to a general population in Stockholm, 2002.
Re-admission

Re-admissions to hospital in AMI patients occur frequently \(^82\): in the Swedish SEPHIA register \(^81\) 30% of patients are re-admitted at least once during the first year, and other investigators have found that approximately 8-10% suffered from a new AMI during the first year \(^19\). It is not known whether poor HRQL affects the re-admission rate in AMI patients. However, in heart failure patients reporting poor HRQL, the re-admission frequency is increased \(^83\). Other individuals at high risk for re-admissions are those of older age, suffering from heart failure, diabetes and depression \(^83-85\).

In Sweden, AMI patients are invited to nurse-led secondary prevention out-clinic visits. Those visits, in addition to visiting a physician, are aimed to prevent re-infarctions and re-admissions by following the secondary prevention guidelines \(^86\). Cardiac rehabilitation nurses are shown to succeed in implementation of those guidelines \(^87\).

The re-admission frequency for the SEPHIA population is shown in Figure 8.
Figure 8. Re-admission frequency from the SEPHIA register.
AIMS

Understanding of why people delay in decision making is limited. Our studies aimed to investigate this topic further in order to:

- gain deeper knowledge and understanding of how patients and relatives think and act during and after symptom onset
- investigate and compare patients’, relatives’ and the general publics’ knowledge of AMI, attitudes to seeking medical care and how they intend to act in case of suspected AMI
- investigate whether self-assessed health related quality of life has any impact on delay time and re-admissions
MATERIAL AND METHODS

Paper I
Design
The study had a descriptive and qualitative design using focus group inter-
views as its research methodology. The author of the thesis informed the
group about the interview guidelines, addressed confidentially, and gave the
participants an introduction. Before starting the interview the participants
were introduced by means of the tape-recording technique.

Population
The participants were patients who had at least one AMI (N=13) and rela-
tives of such patients (N=14). The median age for the patients was 63 years
(range 56–73 years) and for the relatives 60 years (range 31–77 years).

Inclusion criteria for patients:
Discharged with the diagnosis of AMI (ICD 10 code)
- Discharged within the last 3 months
- Age 50-75 years

Inclusion criteria for relatives:
- Someone who was reported as a close relative by the patient
- Had been contacted by a patient at symptom onset

The patients were recruited by asking for their interest in participation. The
relatives were friends or someone close to the patient who fulfilled the
inclusion criteria. They were identified by asking the patients if they had
consulted anyone during symptom presentation.
The eligible participant was contacted either in person or by telephone.
Thereafter they were informed about the study and received written informa-
tion.
The groups were divided by age and gender into three patient groups (1 female and 2 male groups) and three groups of relatives (2 female and 1 male groups). In each group there were 3-7 participants.

Procedure

The participants were recruited between September 2004 and February 2005 at the Department of Cardiology at Uppsala University Hospital. Thirty-eight people were invited to participate in the study and of these, 11 could not or did not want to participate. The focus group interview took place in a conference room near the hospital, and the participants met once. On arrival, the participants signed a written informed consent and completed a form about their background data, including medical history. The interview lasted about one hour and was tape-recorded. The two main questions for the session were:
- “What did you think when the symptoms started?”
- “How did you act during symptom presentation?”

The choice of transportation to hospital was also discussed with all groups. After the interviews the tapes were transcribed verbatim.

Papers II and III

Design

These two studies were multi-centre, cross-sectional with a quantitative, descriptive and comparative design using questionnaires as the instrument.

Population

In Paper II, six Swedish hospitals recruited patients and relatives to the study.

Inclusion criteria for patients:
- Discharged with the diagnosis of AMI (ICD 10 code)
- Discharged from a Cardiology Department < 1 year
- ≤ 75 years old
- Living within the hospital’s catchment area

Inclusion criteria for relatives:
- Named as a close relative in the patient’s medical record.
- A friend or close relative to a patient who fulfilled the inclusion criteria and who had been discharged alive.
Exclusion criterion for relatives:

- A friend or close relative to a patient included in the survey.

In *Paper III*, four of the six hospitals participating in *Paper II* enrolled patients to the study. The inclusion criteria and patient population were the same as in *Paper II*. A population matched to the patients with regard to age, gender and catchment area represented the general public group. The participants in the latter group had to be \( \leq 75 \) years, living within the catchment area with no history of AMI.

Procedure

The questionnaires were based on the results in *Paper I* and were specially developed for these studies in collaboration with two experts in the field. The questionnaires contained questions about symptoms, delay time, determining factors for medical care seeking and background characteristics. Non-relevant questions for relatives and the general public were excluded. Questions regarding background characteristics were formed as force-choice response alternatives: yes, no or do not know. Knowledge and attitude questions were formed as statements about intended actions and were answered on modified visual analogue scales (VAS), ranging from 1 (“Don’t agree at all”) to 5 (“Agree”).

When processing the results, chest discomfort/pressure/pain was presented as chest pain.

For testing validity, the questionnaire contained 16 statements of the participant’s intended action if they suffered an arm fracture. The answers to those questions were expected to differ from answers related to a suspected AMI.

To attain answers from 300 patients and 300 relatives, at least 450 questionnaires (75 at each hospital) were distributed to each group (Figure 9). At an incidence of 50% of a specific variable, the “true” frequency of this variable in the population (*Paper II*) would be in the interval between 44-56% with a 95% probability given a sample size of 300, and at an incidence of 10%, the similar 95% confidence interval would be 6.5-13.5%.

For *Paper III*, 700 questionnaires were distributed to the general public. With a 95% probability given a sample size of at least 200, at an incidence of 50%, the interval would be 42-58% and at an incidence of 10%, the similar 95% confidence interval will be 6.3-13.7.

Three university hospitals and three county hospitals recruited patients and relatives (*Paper II*). For recruiting participants to the general public group, the catchment areas of two of the university hospitals and two of the county hospitals were used (*Paper III*).

To find data of patients and relatives (*Paper II*), a nurse at each hospital searched in the RIKS-HIA register for eligible patients according to the in-
clusion criteria. Every second patient on the list was selected to the patient group, and for the name in between a relative of that patient was chosen for the relative group. The closest relatives were identified from the patient’s medical record and addresses were found in the patient administration system or the telephone directory.

Nurses at the participating hospitals forwarded the lists including names and addresses of eligible patients and relatives. The Swedish national population register was used to find a group representative of the general public, (Paper III). Five individuals were matched to every participating patient with respect to age, gender and catchment areas. We estimated that three of these five people would be enough to attain a sufficient number of participants. An external company did the matching process and produced lists with names and addresses of the eligible representatives from the general public.

Invitation letters were sent to the patients and relatives (Paper II) between the end of August 2006 and January 2007 including information about the study, the questionnaire and a pre-paid return envelope. The general public group received the questionnaires in April - May 2007 (Paper III). One reminder was sent 2-4 weeks after the first invitation to those who did not respond the first time. When the answers were received, the lists with the identification details of all participants were destroyed so participants remained anonymous.

The response rate was 76% for patients, 70% for relatives and 59% for the general public.
Figure 9. Questionnaire distribution and rate of answers in Papers II and III.

Paper IV
Design
This study was a multi-centre, register study based on information from the national quality registers RIKS-HIA (The Register of Information and Knowledge about Swedish Heart Intensive Care Admissions) and SEPHIA (Secondary Prevention after Heart Intensive Care Admission).

Population
AMI patients (ICD-code I21, I22), < 75 years old were included in this study. They had to be admitted to hospital and registered in RIKS-HIA and SEPHIA within the period 2005-2009. There were 45,868 AMI patients < 75 years registered in RIKS-HIA during this period, and 28,214 patients offered to participate in SEPHIA. Of these patients, 18,015 had at least one registered 1-year follow-up in SEPHIA. Two sub-sets of this population were included in the study, one for the evaluation of the association between HRQL and delay time (“Delay Time Population”) and one for the evaluation
of the association between HRQL and re-admissions ("Re-admission Population").

The Delay Time Population consisted of patients who had an AMI registered in RIKS-HIA and a 1-year follow-up registration in SEPHIA, including HRQL measurement. Thereafter an additional AMI was registered in RIKS-HIA (n=454). In addition, the Re-admission Population had also completed the 1-year follow-up registration in SEPHIA after the new AMI (n=216), Figure 10.

**Figure 10. Flow chart of the study population**

**Procedure**

Patient data were obtained from the national quality registers RIKS-HIA and SEPHIA within the period 2005-01-01 – 2009-12-31. Nurses and doctors at each hospital collected and entered all data after interviewing patients.

**RIKS-HIA** (The Register of Information and Knowledge about Swedish Heart Intensive Care Admissions).

More than 95% of all AMI patients admitted to a Department of Cardiology in Sweden are registered in RIKS-HIA. Patient information is reported every day on case report forms and is transmitted into an on-line database. The variables of age, gender, risk factors for coronary heart disease, medical history, medications, symptoms, time of symptom onset, time of admission and ECG findings at admission to the Cardiology Department are noted. During the hospital stay biochemical markers, treatments, investigations and complications are entered and at discharge the variables outcomes, medications and diagnosis are recorded.
SEPHIA (Secondary Prevention after Heart Intensive Care Admission)
These patients must be enrolled in RIKS-HIA for creating a follow-up in the secondary prevention register (SEPHIA). Myocardial infarction-patients <75 years were followed up in SEPHIA. There were two out-patient clinic visits or telephone contacts for every eligible patient. The first follow-up occurred 6-10 weeks after discharge, and the second follow-up 12-14 months after discharge. Recorded variables consisted of health-related quality of life measured by EQ-5D, cardiac-related symptoms occupation, re-admissions, recurrence, investigation/treatment after discharge, risk factors such as smoking, weight, waist-circumference and level of physical activity. Measurements of blood pressure, lipids, HbA1c in diabetic patients, participation in secondary prevention programmes and compliance to medication were all noted.

The study populations reported their estimated HRQL at each follow-up visit. The one-year follow-up after the initial AMI was considered to represent the patient’s HRQL before the new AMI.

EQ-5D was measured in median 325 (25th-75th percentile; 125 – 604) days before the new AMI.

Definitions

*Time from symptom onset:* The time of onset of patient’s last episode of symptoms before taking the decision to seek medical care.

*Patient’s delay time:* The time from symptom onset to hospital arrival.

*Hospital admission time:* The patient’s arrival time at the Emergency Department, Cardiology Department directly or the PCI-unit directly, whichever was the first.

*Re-admissions:* all re-admissions to hospital regardless of diagnosis.
ANALYSIS

Paper I
After transcription of the material, the text was analysed by means of qualitative content analysis. Words and sentences containing information relevant to the aims of the study were identified and classified as meaning units. The meaning units were then condensed and grouped to form subcategories, and were finally deployed to build main categories. The content of the main categories were examined in collaboration with one co-author and some adjustments thereafter were made.
To ensure the true value of the data analysis, data were collected and analysed by the same person. A person with prior experience of content analysis categorised the meaning units according to the description of the categories and we then compared the results, achieving good agreement (Cohen’s Kappa value=0.90).

Papers II & III
For the analysis of items related to knowledge and attitude, the VAS-scales were transformed into 9 grades (1, 1.5, 2…… 4.5, 5) ranging from 1 (“Do not agree at all”) to 5 (Agree). Answers ≥ 3.5 on the VAS scale were considered as agreement. In Paper II, seventeen knowledge and 34 attitude questions were summarised by computing mean scores for knowledge and attitudes respectively. We then compared the patient and relative groups (Paper II), and the patients and the general public (Paper III). The populations (patients, relatives and general population) were limited to those who had an internal response rate of at least 80%.
The Chi Square and the Mann-Whitney U-test were utilised to examine differences between the groups. For paired comparisons we used the Wilcoxon’s test. Due to multiple comparisons, significance was set at p ≤.01. For all statistical analysis the Statistical Package for Social Sciences (SPSS) version 14.0 was used.
Continuous variables are reported as medians with 25th and 75th percentiles (Q1, Q3) and categorical variables are reported as frequencies and percentages. Spearman’s rank-order correlation (rho) was used to describe the relationship between EQ-VAS and EQ-index. Models with delay time as an outcome were adjusted for age, ambulance, diabetes, gender, history of heart failure, hypertension, pre-hospital ECG, previous PCI, previous stroke, previous CABG, pulmonary rales, reperfusion treatment, STEMI and year. The models with re-admission as an outcome were adjusted for the same variables as delay time but also for the number of medications at discharge after the new event and PCI during hospital but not for pulmonary rales and reperfusion treatment. Results from the logistic regression models were presented as estimated odds ratios (OR) with 95% confidence intervals, and a p-value for test of the null hypothesis that the true odds ratio is unity. The median time between 1-year follow-up in SEPHIA and date of a new AMI registered in RIKS-HIA was 325 days (25:e-75:e perc=125-604) and was classified into short (<325 days) and long (≥325) time. All statistical tests and confidence intervals are two-sided and p<0.05 was considered statistically significant. All calculations were performed with SAS Version 9.2 (SAS Institute Inc., Cary, NC, U.S.A.).
RESULTS

Paper I

After analysing the results, six categories emerged:

1. Symptoms of pain and discomfort
The study patients experienced several symptoms. The feeling of uncertainty of symptom origin was common in both patients and relatives. Strong pain influences the decision to seek medical care.

2. Thoughts and interpretation of symptoms
Patients who had previously received information about AMI had a better understanding of symptom origin than others. The symptoms experienced were commonly explained as a less serious condition and believed to be too mild to be a heart attack. The relatives often felt unsure about how to act.

3. Self-care and actions in response to symptoms
The most common delaying actions were trying to alleviate symptoms on their own and to rest. When symptoms remained, patients often consulted an additional person for advice. Female patients had a need to organize things at home and to be clean and tidy before going to hospital. Relatives often persuaded their close one to seek medical care.

4. Contacting someone else
The closest relative, in some cases, consulted an additional person before they decided to seek medical care.

5. Feelings of fear and uncertainty
Feelings of uncertainty and anxiety were commonly experienced. Relatives expressed anxiety more frequently than the patients.

6. Seeking and receiving medical care
The decision to call the alarm number was often taken by the relatives. Those who did not call the alarm number thought they had no right to take
an ambulance just because of a little stomach/chest pain, or believed it took too long to wait for an ambulance.

Paper II

Background characteristics and action taken
The investigation groups consisted of 364 AMI patients and 319 relatives of AMI patients (Table 1). Relatives had higher educational levels than patients. Patients’ median delay time, from symptom onset to contacting medical care, was 45 minutes. There were no significant differences in delay time in relation to age, gender or previous AMI. The most common factors for the decision to seek medical care were pain and an understanding of the severity of the situation. Less than half of the patients called the alarm number as their initial action. One quarter was driven in a private car and 47% of the patients consulted an additional person at symptom onset, before contacting health care providers.

Table 1. Background characteristics. Patients and relatives.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Patients (n=364)</th>
<th>Relatives (n=319)</th>
<th>RIKS-HIA (n=10 710)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women %</td>
<td>23</td>
<td>73</td>
<td>28</td>
</tr>
<tr>
<td>Age (median)</td>
<td>64 (59-69)</td>
<td>61 (53-67)</td>
<td>64 (57-70)</td>
</tr>
<tr>
<td>Education &gt; 9 years %</td>
<td>49</td>
<td>63</td>
<td>No data</td>
</tr>
<tr>
<td>Prior AMI* %</td>
<td>28</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>Angina %</td>
<td>34</td>
<td>6</td>
<td>No data</td>
</tr>
<tr>
<td>PCI ** %</td>
<td>83</td>
<td>3</td>
<td>68</td>
</tr>
<tr>
<td>CABG ** %</td>
<td>15</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Known diabetes %</td>
<td>19</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td>Smoker + Ex-smoker %</td>
<td>55</td>
<td>45</td>
<td>66</td>
</tr>
</tbody>
</table>

Data from the national quality register RIKS-HIA, patients ≤75 years (2007)
* Before the present hospitalisation.
** Percutaneous Coronary Intervention and Coronary Artery Bypass Grafting, including procedure at the present hospitalisation.

Knowledge
There were no significant differences in understanding of probable AMI-symptoms between patients and relatives, except for the relatives’ better knowledge about chest pain and radiating pain in left arm. Women had better knowledge of AMI than men. The elderly, more commonly than younger individuals, thought that an AMI always starts suddenly.

Intended actions and attitudes
Patients with prior AMI had the same attitudes as first time AMI patients. If consulted by someone experiencing chest pain, the majority of participants
would not wait before contacting medical care. The majority of both patients and relatives believed they would call for an ambulance in the case of self-experienced chest pain or being present when someone else suffered from such symptom, with no differences between the groups. Respondents were more likely to report appropriate actions if someone else suffered from AMI-symptoms compared to self-experienced symptoms.

**Intended actions and attitudes divided by gender and age**

Women in comparison to men would more often wait before seeking medical care in the case of their own chest pain, and would also more commonly contact another person before consulting medical care. Elderly persons would call the alarm number in case of self-experienced chest pain to a greater extent than younger people. Overall, no large differences were found regarding age, gender and attitudes.

**Paper III**

**Background characteristics** (Table 2)

The participants consisted of 246 AMI patients and 418 representatives from the general public. The median age and gender distribution was equal in both groups. The general public had higher educational levels than the patients.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Patients (N=246)</th>
<th>General public (N=418)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women %</td>
<td>24</td>
<td>27</td>
</tr>
<tr>
<td>Age (median)</td>
<td>65 (31-75)</td>
<td>65 (31-76)</td>
</tr>
<tr>
<td>Education &gt; 9 years %</td>
<td>51</td>
<td>61</td>
</tr>
<tr>
<td>Prior AMI* %</td>
<td>28</td>
<td>No data</td>
</tr>
<tr>
<td>Angina %</td>
<td>32</td>
<td>4</td>
</tr>
<tr>
<td>PCI ** %</td>
<td>83</td>
<td>2</td>
</tr>
<tr>
<td>CABG** %</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Known diabetes %</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td>Smoker + Ex-smoker %</td>
<td>54</td>
<td>39</td>
</tr>
</tbody>
</table>

* Before the present hospitalisation.
** Percutaneous Coronary Intervention and Coronary Artery Bypass Grafting, including procedure at the present hospitalisation.

**Knowledge**

No large differences regarding knowledge of AMI-symptoms were found between patients and the general public (Figure 11). The majority of the participants thought that an AMI always starts suddenly, with no differences between the groups. The general public group had better knowledge of the
time dependency for treatment outcome for an AMI compared to the patients.

![Knowledge about AMI-symptoms](image)

**Figure 11.** Knowledge of AMI-symptoms by patients and the general public.

**Intended actions and attitudes**
The majority of both patients and the general population would call the alarm number if they suffered from self-experienced chest pain. However, a higher proportion of participants would call the alarm number if someone else suffered from chest pain. The general public would use transportation services other than an ambulance in case of self-experienced chest pain more often than the patients.

Few participants reported that they would wait before seeking medical care. However, the general public would more commonly wait before medical care seeking than the patients. They would also believe more often that waiting times at the Emergency Department are always long. Neither patients nor the general public considered it embarrassing to seek medical care even if they did not know if it was a heart attack causing the symptoms.

**General public data divided by gender and age**
Female representatives of the general public had better knowledge of the symptoms of back pain, nausea and abdominal pain. No gender differences were seen regarding calling the alarm number. Neither men nor women supposed they would wait before seeking medical care in the case of their own chest pain.
Age had no influence on calling the alarm number if someone else suffered from chest pain. However, if experiencing their own symptoms elderly people (66-75 years) tended to call the alarm number more frequently than younger. To a greater extent, the elderly would act more appropriately in cases of chest pain.

**Paper IV**

**Background characteristics**
The median age was comparable in both the study populations and the total SEPHIA population. The study patients were generally sicker and had shorter delay time in comparison to the SEPHIA population.

**Health-related Quality of Life measurements**
The total SEPHIA population reported higher EQ-5D scores than the study populations.

There was a moderate correlation between EQ-index and EQ-VAS, Spearman’s rho = 0.57 (p<0.001), both in the Delay Time Population and the total SEPHIA population. The correlation between EQ-VAS and the different sub-components of EQ-index was also modest, and Spearman’s rho varied between -0.27 and -0.47.

**Delay time and Health-related Quality of Life**
The majority of patients in the study delayed for more than two hours from symptom onset to hospital arrival. Patients who scored EQ-VAS ≤ 50 had an unadjusted odds ratio (OR) for a delay of ≥ 2 hours before hospital admission of 2.86 (95% CI: 1.47-5.54), and an adjusted OR of 3.01 (95% CI: 1.43-6.34), compared to those who scored EQ-VAS 81-100.

There was no significant interaction between gender and EQ-VAS (p=0.29) or EQ-index (p=0.30).

The closer in time the HRQL measurement was to the new AMI, a tendency to a stronger relationship was seen between EQ-VAS and delay time. Patients who experienced a new AMI within 325 days from the initial EQ-5D measurement and scored EQ-VAS ≤ 50, had an adjusted OR of 4.40 (95% CI: 1.40-13.9) for a delay time ≥ 2 hours. Conversely, in patients who had a new AMI more than 325 days after the EQ-5D measurement, the corresponding adjusted OR was 2.52 (95% CI: 1.08-5.89).

Neither the EQ-index nor the separate EQ-5D dimension of anxiety/depression had any significant influence on delay time.
Re-admission and Health-related Quality of Life

In this study population, 40% were re-admitted to hospital at least once within the first year. Patients who reported EQ-VAS ≤ 50 had an increased risk of re-admissions compared to those reporting EQ-VAS 81-100 in the univariate model (OR 3.08, 95% CI: 1.71- 5.53). However, after adjustment the OR decreased (1.99, 95% CI: 0.90 - 4.38) and was no longer significant.
DISCUSSION

There are few investigations aimed at evaluating and comparing patients’, relatives’ and the general public’s knowledge of AMI and their intended actions and attitudes when an AMI occurs. Similarly, AMI patients’ HRQL has been examined infrequently in relation to delay time and re-admissions.

Knowledge and symptoms

Our results show that the participating patients were no more knowledgeable about AMI than relatives or representatives of the general public (Papers II and III). Patients were expected to have better awareness of the illness after receiving information in hospital. However, the general public knew more about the time-dependency in treatment outcomes than patients did (Paper III). This is a surprising result and might be explained by higher educational levels in the sample of the general public.

Both symptom presentation and recognition appear to influence health-seeking behaviour. Recognition of symptoms and severe symptoms with abrupt onset are factors that decrease the delay time. Participants in Papers II and III had good awareness of chest pain and radiating pain in the left arm as symptoms of an AMI, but lacked awareness of other, commonly occurring symptoms. This supports previous investigations. People often misinterpret symptoms, and the expected symptoms do not always match those experienced. In Papers I and II, pain was an important reason for seeking medical care. Understanding of symptom severity was one common reason why patients in our first study sought care. This is important since other authors have found that patients who understand the seriousness of the situation and believe it is the heart causing the symptoms, have a shorter delay time.

More than half of the participants (patients and general public) in Paper III thought that an AMI always started suddenly. This misunderstanding may come from movies where patients with AMI often have dramatic symptom onset. It is important to inform people about the fact that less than 50% of all AMI cases start suddenly.
Intended actions and attitudes to medical care seeking

It is well-known that patients often wait for hours before seeking medical care \cite{13,45,91}, but only a minor portion of the participants in Paper II and III expected that they would wait in case of AMI-symptoms. Patients in Paper II with prior AMI did not seek medical care any faster than first time AMI patients. It is known that patients with previous experience of an AMI are more likely to misinterpret new symptoms \cite{92}, and if a patient seeks medical care with false alarm symptoms, they often delay in the future \cite{28}.

The finding in Paper I, showing that patients might try to alleviate the symptoms themselves before consulting medical care, conforms with previous studies and increases the delay further \cite{39,44}. One possible explanation for this action might be the advice from the hospital to take two Nitroglycerine and wait. Other possible causes for delay are being unsure about symptom origin and denial \cite{41,53}.

Despite people’s relatively good knowledge of AMI-symptoms, our results confirm other investigations \cite{39,41}, which have found that patients are often unsure about how best to act and often need advice and support before seeking medical care (Papers I and II).

A large proportion of the participants in Paper III believed they would seek medical care urgently even if they did not “know” that it was the heart causing the symptoms. This result contradicts experiences from everyday clinical work when patients often mention they would feel embarrassed if the symptoms were not considered serious when arriving at hospital. Feelings of embarrassment probably occur more often in situations of insecurity. Feeling embarrassed to call the alarm number is known to increase patients’ delay time \cite{39}.

The general public, more often than patients, thought there would always be a long waiting time at the ED, regardless of what kind of illness they were seeking care for (Paper III). This result is probably influenced by patients’ prior experience, and it is important to inform the general public that cases of suspected AMI are given priority in the ED.

People’s intended action in a hypothetical situation seems to be appropriate, but when an event really occurs they often do not act as expected. In a non-critical situation, people probably know how to act but in case of an acute event, several emotions influence the decision-making process. Ignorance of symptoms and denial prolong the delay time \cite{53,54}.

An interesting result in Paper II was that patients and relatives reported they would act more appropriately if they were present when someone else experienced AMI-symptoms, compared to self-experienced symptoms. It seems to be easier to neglect and underestimate the seriousness of one’s own symptoms, in comparison to another person’s illness. Defence mechanisms
are probably more prevalent in individuals suffering from symptoms, which may explain why people close to a patient would act more appropriately.

Our first paper confirms previous research, showing that relatives seem to experience more anxiety than patients do, maybe because of their more realistic view of the situation. Anxiety in relatives is associated with decreasing patients’ psychosocial adjustment to illness, but education sessions aimed at reducing anxiety resulted in lower levels of anxiousness in ischemic heart disease-patients. If people in general had a better understanding of how to act in AMI cases, the insecurity and anxiety would decrease and people would probably act faster.

The majority of patients, relatives (Paper II) and the general public (Paper III) reported that they would call for an ambulance in the event of chest pain, but in reality only about half of all AMI patients call the emergency number. One factor for not ordering an ambulance is that patients do not consider their illness serious enough. A large proportion of participants knew the importance of calling the emergency number in the event of AMI-symptoms (Papers II and III), but knowledge alone does not guarantee appropriate action. Participants in Paper I gave several explanations for not ordering an ambulance: it takes too long to wait for an ambulance or the transporting distance was too far for ordering an ambulance. On the other hand, some participants preferred to use an ambulance because it is a faster transportation mode. However, the participants did not discuss other ambulance advantages like pain-relieving treatment, life-saving equipment and the ability to communicate directly with a physician at the hospital and to receive acute medical treatment much faster. Previous research show that patients arriving at the hospital by ambulance have shorter delay times.

One surprising finding was that only a few participants believed they would refrain from ordering an ambulance because the attention would be embarrassing (Paper III). In reality, this argument is heard from several patients, and those who feel embarrassed have an increased delay time.

Patients and relatives (Paper II) would more commonly call the emergency number for others, but would delay calling for their own symptoms, this finding has been shown in previous studies. It was often the relatives (Paper I) who took the decision to call the emergency number: they might have a more objective view of the event and probably have less denial than the patients. Relatives were unwilling to take responsibility for failing to order an ambulance in the event of severe illness, and probably therefore acted more appropriately.
Gender

Women were more knowledgeable about AMI than men (Paper II), which is in accordance with other results. Female representatives of the general public had a better understanding of those AMI-symptoms more commonly experienced among women (Paper III). Maybe women are more aware of several disorders and more interested in health-related issues, especially if their spouse suffers from AMI-symptoms. It was surprising that no gender differences were found regarding waiting before seeking medical care in the general population (Paper III), but in Paper II both female patients and relatives supposed they would wait before seeking medical care. In one study by Meischke et al., females reported they would act appropriately and quickly in response to symptoms. However, despite females’ better understanding of AMI, they often delay for a longer time than men. It is uncertain whether women’s increased delay time really depends on female gender or if it depends on their older age when having an AMI, since previous investigations have shown that older patients delay for longer time. Some reasons for delay, especially in female patients, were their estimation of the importance of organising things at home and being clean and tidy before going to hospital (Paper I). Another factor for delay in women was their need to consult a further person before medical care seeking (Paper II), which might be explained as insecurity, despite their better knowledge. One author report that male patients often consult their spouse before seeking medical care, and female patients more commonly contact other family members. This might partly explain the male’s shorter decision time since spouses, in comparison to children, are often close by and probably have more influence on the decision to seek medical care.

Age

A higher proportion of elderly patients and relatives, in comparison to younger, thought that an AMI always started suddenly (Paper II). This misunderstanding must be emphasized, since older people often experience ambiguous and vaguer symptoms. It is thus important to inform them about the risk of an AMI if suffering from such symptoms. Younger participants (Papers II and III) would act less appropriately than the elderly in the medical care seeking process. Older people probably know several friends who have told them about own experiences of an AMI. Elderly people may have more interest in learning about various kinds of disorders and more commonly understand their higher risk of having a serious condition, which makes them more watchful.
Health-Related Quality of Life

In the study populations in Paper IV who had experienced at least two AMIs, the EQ-5D scores were comparable to those of the total SEPHIA population, and also in comparison to another study examining HRQL in AMI patients. People in general score higher HRQL than AMI patients do. An AMI is often believed to be stressful, and stress sometimes results in anxiety and/or depression. Those emotions are known to decrease HRQL.

Health-Related Quality of Life measurements (EQ-5D)

The EQ-5D was measured one year after the initial AMI, and in median 325 days before the new event. The reported EQ-5D-scores were considered to represent the patients’ HRQL at the time of the new AMI. The timing when measuring HRQL seems to influence the results and HRQL measured in other investigations has shown that patients indicated improved HRQL from hospitalisation up to one year post-AMI. In previous SEPHIA data there are small differences in EQ-VAS and EQ-index between the first and second follow-ups. Our study populations had a worse HRQL than the total SEPHIA population, which might relate to their sicker condition and several co-morbidities. EQ-index and EQ-VAS do not seem to be completely comparable. The correlation between EQ-index and EQ-VAS was low to moderate in previous investigations as well as in this current study. The response alternatives in EQ-index and EQ-VAS differ, probably to the advantage of the EQ-VAS scale, giving the opportunity to answer in a range from 0-100, compared to the EQ-5D dimensions limited to only three forced-choice alternatives.

Delay time and Health-Related Quality of Life

Sixty per cent of the patients included in the study delayed more than two hours before arriving at hospital, despite several hospital admissions containing information about how to act in case of a future event. It is known that many people try to avoid stimuli associated with past unpleasant experiences, and therefore delay seeking medical care. Possible reasons why patients who scored low on total health status have longer delay times might be that their poor total health status is a result of depression, and as could be expected, depressed patients are seen to have longer delay times. Patients with symptoms of depression are also known to have less motivation to seek medical care, and they also commonly
consult another person before going to hospital, an action that is known to delay the time to hospital further. However, the lack of correlation between the EQ-5D dimension anxiety/depression and delay suggests that depression is not a major underlying cause behind the association between EQ-VAS and delay time. Given the low number of patients scoring more severe anxiety/depression, the lack of association should be interpreted cautiously.

Only EQ-VAS showed significant correlations with delay time: the EQ-index had no importance. EQ-VAS probably reflects other factors of importance than the EQ-index does.

**Re-admission and Health-Related Quality of Life**

The study population had a slightly higher re-admission frequency than the SEPHIA population, which might reflect the worse health status of the study patients. Hospital admissions are shown to increase in those with co-morbidities and in depressed patients. In the univariate analysis, patients who scored poor total health status had a higher risk of re-admissions within the first year, but we could not verify this result in the multivariate analysis. The ability to show an independent correlation was limited, which might be explained by the relatively small study group of 216 patients.

**Method discussion and limitations**

**Paper I**

Focus group interviews is a suitable qualitative method to use in exploratory research and as a foundation for further studies. The fact that participants only were recruited from one hospital was a limitation of the study.

In qualitative research the reliability and validity is described by credibility, dependability and transferability. To reach trustworthiness in this paper the methodology is described in detail, all interviews were performed by the same person, the results were reviewed by and discussed with a co-author and consensus about the categorization was reached. The comparison of the categorisation between the first author of the thesis and one co-author had good agreement when using the Kappa statistics.
Papers II and III

The advantages of the studies in Papers II and III were the random selection of patients, relatives and representatives of the general public, and the fact that the recruited participants came from different geographical areas in Sweden. The age limit of 75 years was chosen to decrease the possibility of influences from other disorders, which might have affected the answers, and therefore the results cannot be generalized for those older than 75 years. The patient recruitment process was limited to those enrolled in the RIKS-HIA register and admitted to a Department of Cardiology. Although the response rate was high, it is possible that the respondents were more interested in and more knowledgeable about the topic under investigation than the non-responders.

The questionnaire was only developed in Swedish, which limited the participation of people with language difficulties. An assessment of a hypothetical situation might differ from a real event. In hypothetical situations people might answer more appropriately compared to a stressful situation such as AMI-symptom onset. This may influence the respondents’ answers.

The questionnaire was not tested for reliability, which was a limitation. However, as expected, there were differences between intended actions in the event of chest pain compared to an arm fracture, and this was interpreted as evidence of good validity.

Paper IV

The results were only valid in patients less than 75 years old, who had experienced more than one AMI and who were registered in RIKS-HIA and SEPHIA. All AMI patients over 75 years including in RIKS-HIA were not enrolled in SEPHIA. Delay time estimates were reported by the patients and do not give an exact time point. However, uncertainties about the time are probably an underestimation of the relationship between HRQL and delay rather than the opposite. There were few missing delay time values. The registers describe real-life circumstances and data were obtained consecutively from all Swedish regions.

The follow-up visit after one year varies between 12-14 months and might affect the patients’ estimated HRQL results.

The lack of correlation between anxiety/depression and delay time should be interpreted with caution due to the small number patients scoring more severe problems. The EQ-index does not appear sensitive enough for evaluating emotions such as anxiety/depression.
CONCLUSIONS

There were few differences in knowledge and attitudes between AMI patients, relatives and the general public. Knowledge does not seem to be the most important factor for decreasing delay time. Patients and relatives often felt uncertainty about both the origin of symptoms and how to act in suspected AMI. The participants would act more appropriately if someone else suffered from chest pain compared to their own symptoms. Patients, compared to the general public, would often act more correctly in the medical care seeking process. People seem to act more appropriately in a hypothetical situation than in real life. Overall there were few differences related to gender and age. AMI patients who reported poor total health status (EQ-VAS ≤50) were at greater risk of delaying for more than two hours than those scoring EQ-VAS 81-100, but there was no independent association between poor total health status and re-admissions during the first year.
CLINICAL IMPLICATIONS

Patients, relatives and the general public need more information about symptom recognition, including typical as well as atypical symptoms and the possibility of intermittent symptom character. Greater awareness is necessary about what action to take, common behaviours including denial, and how those might be characterised.

Patients who report poor total health status have to be identified and given more support and information.

The gap between intended and real actions can be reduced by detailed, individualized information. Both written and verbal information should be provided. Positive messages should be given about the advantages of cardiac muscle salvage when fast treatment is received, and the decreased risk of complications when treated rapidly. Education should also include why it is so important to call the emergency number quickly.

Further investigations on this topic are needed before improved, specific recommendations can be produced on how to reach a significant reduction in patient delay time.
Risken att avlida i hjärtinfarkt är störst under de första timmarna och majoriteten av patienter som avlider på grund av hjärtinfarkt dör innan de kommit till sjukhus. Att snabbt komma under övervakning och få behandling är viktigt för att minska infarktskanalen och öka överlevnaden. Många patienter väntar dock flera timmar efter symtomdebuten innan de söker sjukvård. Orsakerna till att patienterna dröjer med att söka vård är inte fullständigt undersökta. Även återinläggning på sjukhus efter en hjärtinfarkt är fortfarande vanligt förekommande även om majoriteten av patienterna idag inte har några kvarstående symtom efter hjärtinfarkten.

Syftet med denna avhandling var att få mer kunskap och förståelse för hur patienter och anhöriga tänker och handlar vid symtom på hjärtinfarkt. Att undersöka och jämföra patienter, anhöriga och allmänhetens kunskap om hjärtinfarkt, attityder till uppsökande av sjukvård och hur de tror att de skulle agera i samband med misstänkta hjärtinfarkt-symtom. Ett ytterligare syfte vara att undersöka om hälsorelaterad livskvalitet har någon betydelse för patientens fördröjningstid och för återinläggning.

Resultaten visade att det var få skillnader i kunskap och attityder mellan hjärtinfarktpatienter, anhöriga och allmänheten. Enbart kunskap verkar inte vara den viktigaste faktorn för att förkorta fördröjningstiden. Patienter och anhöriga kände sig ofta osäkra både beträffande vad symtomen berodde på och hur de skulle agera i samband med insjuknandet. Deltagarna i delarbete II och III skulle agera mera korrekt om någon annan än de själva drabbades av bröstsmärta. I en hypotetisk situation bedömer folk att de skulle agera mer korrekt än vad de i verkligheten gör om händelsen inträffar. Det var få skillnader i relation till ålder och kön.

Hjärtinfarktpatienter som i samband med återbesök upplevde dåligt totalt hälsostatus (EQ-VAS <50) hade högre risk att vänta mer än två timmar, från symptomdebut till sjukhusankomst, i de fall de drabbades av en ny hjärtinfarkt, jämfört med dem som skattade ett bra hälsostatus (EQ-VAS 81-100). Däremot kunde inget oberoende samband påvisas mellan dåligt totalt hälsostatus och återinläggning inom det första året.
Mer information behöver ges till både patienter, anhöriga och allmänheten gällande symtom, rekommenderat handlingssätt vid symtom på hjärtinfarkt och vanligt förekommande beteenden såsom förträngning. Vidare bör patienten informeras om betydelsen av att behandling sätts in tidigt för att minimera hjärtskadan.

Nya metoder och strategier med syfte att minska patienternas fördröjningstid behöver utvecklas och utvärderas i större kliniska studier.
ACKNOWLEDGEMENTS

I want to express my sincere gratitude to all those who contributed to the accomplishment of this thesis, with special thanks to:

**Bertil Lindahl**, my supervisor, for teaching me medical science, for sharing some of your broad knowledge of cardiology and clinical research, and for your never-ending enthusiasm, patience and effectiveness.

**Margareta Larsson**, my co-supervisor, for all your support, for being available for all my questions and for discussions, and for teaching me in several research methods.

**Lars Wallentin**, my boss when I started writing my thesis, for your encouragement and generosity and for giving me the opportunity to take part in the ischemic heart disease research group.

**Lisa Wernroth**, my colleague at UCR and co-author of Papers II-IV, for statistical support and collaboration and for your patience with all my statistical questions.

**Matts Högberg, Ingrid Mårtensson and Anita Öström**, colleagues and friends at UCR, for your professional support.

All co-authors for great encouragement, inspiration and kindness.

Members of the ischemic heart disease research group, for support and collaboration throughout the years.

The nurses at each participating hospital for supporting me when searching for participants for Paper II.

My colleagues and friends at UCR and the Department of Cardiology for your kindness, support and for all our great cooperation and fun.

All my friends in Uppsala and Östergötland who have taken me to activities other than working with my thesis. This was much needed.

And last but not least, my mother **Gun-Brith**, for all your great support throughout my life.
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Supplement 1: Questionnaire (patients)

Background factors

1. Year of Birth ……………

2. Gender
   □ Male        □ Female

3. Civil status
   □ Married/living together □ Living alone

   □ Other …………

4. Do you have any children?    □ Yes    □ No

5. Highest education completed
   □ Comprehensive school/ Elementary school
   □ Senior high school/Equivalent □ University/College

6. Accommodation
   a) □ House □ Rented apartment or flat
   □ Owner flat
   b) □ Urban area □ Rural area

7. History of disease
   a. Have you experienced more than one myocardial infarction?
      □ Yes    □ No
b. Have you had vascular spasm?
   □ Yes    □ No

c. Have you undergone a balloon dilatation (PCI)?    □ Yes    □ No

d. Have you undergone a bypass operation?    □ Yes    □ No

e. Are you having treatment for high blood pressure?    □ Yes    □ No

f. Do you have diabetes?    □ Yes    □ No

g. Are you being treated for high cholesterol?    □ Yes    □ No

h. Do you smoke?    □ Yes    □ No    □ Ex-smoker

i. Do you take snuff?    □ Yes    □ No    □ Ex-snuff taker

8. Which of the following symptoms did you experience during the (latest) myocardial infarction?

Please mark the symptom/s that were present at the onset of illness. *You can mark more than one.*

□ Discomfort/pressure/pain in the chest    □ Discomfort/pain in the back

□ Discomfort/pain in the stomach    □ Discomfort/pain in one or both arms

□ Discomfort/pain in jaws    □ Discomfort/pain in the neck

□ Discomfort/pain in one or both legs    □ Cold sweat

□ Headache    □ Respiratory distress

□ Vertigo    □ Nausea

□ Fainting    □ No symptoms

□ Other ...........................................................................................................
9 a. Did you, by yourself, contact any medical service institution or call an ambulance?

☐ Yes  ☐ No

9 b. If “no”, who contacted the medical service/called an ambulance?

☐ Husband/wife/partner  ☐ Children  ☐ Workmate
☐ Neighbour  ☐ Acquaintance/relative
☐ Unknown  ☐ Other ……………………..

10. How long did you wait before seeking medical care or calling an ambulance?

……………… hours  ……………. minutes  ☐ Don’t know

11. What kind of medical service did you first contact?

☐ Primary Care Unit  ☐ Company doctor
☐ Information hotline for medical care  ☐ Called emergency number
☐ Emergency Dept.  ☐ Other ……………………..
12. What was your determining factor for seeking medical care?

Mark one alternative only.

☐ The pain ☐ Symptoms other than the pain
☐ Was persuaded to seek help ☐ Understood the seriousness
☐ Felt unsure of what it was ☐ Discomfort in the chest
☐ Fear of serious disease ☐ Other reason ………………………

13. Which type of transportation did you use to go to the first medical service?
(Hospital/Primary Care Unit)

☐ Drove my own car ☐ Was driven by private car ☐ Taxi
☐ Ambulance ☐ Other ……………………

A number of statements follow where we want your spontaneous understanding. Please answer all statements.

14. Factors which can influence the risk of having a myocardial infarction.

Mark one box with a cross to describe how well you think the statement agrees with your understanding.

a. Low blood pressure increases the risk of having a myocardial infarction.

Don’t agree at all ———————————————————— Agree completely

b. Smoking increases the risk of having a myocardial infarction.

Don’t agree at all ———————————————————— Agree completely

c. Walking can prevent having a myocardial infarction.

Don’t agree at all ———————————————————— Agree completely
d. Fibrous food can prevent having a myocardial infarction.

Don’t agree at all ---------------------------------------- Agree completely

Mark one box with a cross to describe how well you think the statement agrees with your understanding.

15. Which symptoms do you think occur during a myocardial infarction?
   Please answer all alternatives.

a. Discomfort/pain in right arm.

Don’t agree at all ---------------------------------------- Agree completely

b. Discomfort/pain in left arm.

Don’t agree at all ---------------------------------------- Agree completely

c. Discomfort/pain in the chest.

Don’t agree at all ---------------------------------------- Agree completely

d. Discomfort/pain in right leg.

Don’t agree at all ---------------------------------------- Agree completely

e. Discomfort/pain in left leg.

Don’t agree at all ---------------------------------------- Agree completely

f. Discomfort/pain in the back.

Don’t agree at all ---------------------------------------- Agree completely
g. Discomfort/pain in the stomach.
   Don’t agree at all ———————————————————— Agree completely

h. Nausea
   Don’t agree at all ———————————————————— Agree completely

i. Headache
   Don’t agree at all ———————————————————— Agree completely

Other …………………………………………………………………………………………………………..

16. What do you think about the following statements?

a. Physical exertion can cause myocardial infarction.
   Don’t agree at all ———————————————————— Agree completely

b. You have to be very ill in order to be taken care of at the emergency department when a suspected myocardial infarction occurs.
   Don’t agree at all ———————————————————— Agree completely

c. A myocardial infarction always starts suddenly.
   Don’t agree at all ———————————————————— Agree completely

d. Time is of no importance when it comes to treatment results for myocardial infarction.
   Don’t agree at all ———————————————————— Agree completely
17. Which equipment do you think you would find in an ambulance?

a. X-ray equipment
   Don’t agree at all __________________________ Agree completely
   ☐ Don’t know

b. ECG
   Don’t agree at all __________________________ Agree completely
   ☐ Don’t know

c. Defibrillator (gives electroconvulsive therapy during cardiac arrest)
   Don’t agree at all __________________________ Agree completely
   ☐ Don’t know

d. Pain-relieving drugs
   Don’t agree at all __________________________ Agree completely
   ☐ Don’t know

e. Ultrasonograph
   Don’t agree at all __________________________ Agree completely
   ☐ Don’t know
A number of statements follow concerning seeking medical care. Please answer how you think you would act as spontaneously as you can, not thinking about what is the most correct answer.

18. If someone in your proximity suddenly experiences discomfort/pressure/pain in the chest without any obvious reason, you will:

a. Call a taxi for transportation to a Primary Care Unit.
   Don’t agree at all ———————————————————— Agree completely

b. Call a taxi for transportation to the Emergency Department.
   Don’t agree at all ———————————————————— Agree completely

c. Call the Information hotline for medical care.
   Don’t agree at all ———————————————————— Agree completely

d. Wait and see if the pain disappears.
   Don’t agree at all ———————————————————— Agree completely

e. Give pain-relieving drugs.
   Don’t agree at all ———————————————————— Agree completely

f. Drive the person to a Primary Care Unit.
   Don’t agree at all ———————————————————— Agree completely

g. Drive the person to the Emergency Department.
   Don’t agree at all ———————————————————— Agree completely

h. Call the emergency number 112.
   Don’t agree at all ———————————————————— Agree completely

64
i. Contact an additional person.

Don’t agree at all ——————————————————— Agree completely

Other ………………………………………………………………………………….

A number of statements follow concerning seeking medical care. Please answer how you think you would act as spontaneously as you can, not thinking about what is the most correct answer.

19. If you suddenly experience discomfort/pressure/pain in the chest without any obvious reason, you will:

a. Call a taxi for transportation to a Primary Care Unit.

Don’t agree at all ——————————————————— Agree completely

b. Call a taxi for transportation to the Emergency Department.

Don’t agree at all ——————————————————— Agree completely

c. Call the Information hotline for medical care.

Don’t agree at all ——————————————————— Agree completely

d. Wait and see if it disappears.

Don’t agree at all ——————————————————— Agree completely

e. Take pain-relieving drugs.

Don’t agree at all ——————————————————— Agree completely
f. Drive yourself to a Primary Care Unit.
   Don’t agree at all ———————————————————— Agree completely

g. Drive yourself to the Emergency Department.
   Don’t agree at all ———————————————————— Agree completely

h. Call the emergency number 112.
   Don’t agree at all ———————————————————— Agree completely

i. Contact an additional person.
   Don’t agree at all ———————————————————— Agree completely

Other ……………………………………………………………………………………………………………………………

A number of statements follow concerning seeking medical care. Please answer how you think you would act as spontaneously as you can, not thinking about what is the most correct answer.

20. If you thought someone in your proximity had a broken arm, you would:

   a. Call a taxi for transportation to a Primary Care Unit.
      Don’t agree at all ———————————————————— Agree completely

   b. Call a taxi for transportation to the Emergency Department.
      Don’t agree at all ———————————————————— Agree completely

   c. Call the Information hotline for medical care.
      Don’t agree at all ———————————————————— Agree completely
d. Give pain-relieving drugs.

Don’t agree at all —— Agree completely

Don’t agree at all —— Agree completely

e. Drive the person to a Primary Care Unit.

Don’t agree at all —— Agree completely

Don’t agree at all —— Agree completely

f. Drive the person to the Emergency Department.

Don’t agree at all —— Agree completely

Don’t agree at all —— Agree completely

g. Call the emergency number 112.

Don’t agree at all —— Agree completely

Don’t agree at all —— Agree completely

h. Contact an additional person.

Don’t agree at all —— Agree completely

Don’t agree at all —— Agree completely

Other …………………………………………………………………………………

A number of statements follow concerning seeking medical care. Please answer how you think you would act as spontaneously as you can, not thinking about what is the most correct answer.

**21. If you thought you yourself had a **broken arm**, you would:**

a. Call a taxi for transportation to a Primary Care Unit.

Don’t agree at all —— Agree completely

Don’t agree at all —— Agree completely

b. Call a taxi for transportation to the Emergency Department.

Don’t agree at all —— Agree completely

Don’t agree at all —— Agree completely
c. Call the Information hotline for medical care.

Don’t agree at all ———————————————————— Agree completely

e. Take pain-relieving drugs.

Don’t agree at all ———————————————————— Agree completely

f. Drive yourself to a Primary Care Unit.

Don’t agree at all ———————————————————— Agree completely

g. Drive yourself to the Emergency Department.

Don’t agree at all ———————————————————— Agree completely

h. Call the emergency number 112.

Don’t agree at all ———————————————————— Agree completely

i. Contact an additional person.

Don’t agree at all ———————————————————— Agree completely

A number of statements follow concerning seeking medical care due to a suspected **myocardial infarction**. Please answer how you think you would act as spontaneously as you can, not thinking about what is the most correct answer.

22
a. It is best to confer with someone else before seeking acute medical care.

Don’t agree at all ———————————————————— Agree completely

b. It is best to go to the hospital by private car.

Don’t agree at all ———————————————————— Agree completely
c. It is best to go to the hospital by ambulance.

Don’t agree at all ———————————————————— Agree completely

d. I would not call for an ambulance because all the attention would be embarrassing.

Don’t agree at all ———————————————————— Agree completely

e. I would not seek acute medical care just because of chest discomfort.

Don’t agree at all ———————————————————— Agree completely

f. I would seek urgent care if the symptoms of discomfort/pressure/pain in the chest came and went.

Don’t agree at all ———————————————————— Agree completely

g. I would seek urgent care if I suddenly experienced discomfort/pressure/pain in the chest.

Don’t agree at all ———————————————————— Agree completely

h. I would call the emergency number 112 if I suffered from discomfort/pressure/pain in the chest.

Don’t agree at all ———————————————————— Agree completely

Other …………………………………………………………………………………………………………………………………………………
A number of statements follow concerning seeking medical care. Please answer how you think you would act as spontaneously as you can, not thinking about what is the most correct answer.

23
a. If someone in my proximity suffered from chest discomfort/pressure/pain I would call the emergency number 112.

Don’t agree at all ——————————————————— Agree completely

b. If someone in my proximity felt ill at night I would wait until the next day before seeking medical care.

Don’t agree at all ——————————————————— Agree completely

c. If I myself felt ill at night I would wait until the next day before seeking medical care.

Don’t agree at all ——————————————————— Agree completely

d. I think people often go to the Emergency Department for insignificant things.

Don’t agree at all ——————————————————— Agree completely

e. It is important to be clean and tidy when going to the Emergency Department.

Don’t agree at all ——————————————————— Agree completely

f. I would not seek urgent care if I didn’t “know” that it was the heart causing the symptoms. It would be embarrassing if the symptoms didn’t involve any dangerous complaint.

Don’t agree at all ——————————————————— Agree completely

g. I think people often use the ambulance for insignificant things.

Don’t agree at all ——————————————————— Agree completely
h. You always have to wait at the Emergency Department, regardless of why you are seeking care.

Don’t agree at all  Agree completely

Comments ........................................................................................................................................

Are you satisfied with the information you have received from the hospital regarding how to act if new symptoms of a myocardial infarction occur?  ☐ Yes  ☐ No

Comments ........................................................................................................................................

Do you have any suggestions about how best to spread information to the general public about the importance of seeking medical care in cases of suspected myocardial infarction?

........................................................................................................................................................

........................................................................................................................................................

Thank you for participating.

Please return the completed questionnaire within two weeks.

If you have any questions please contact one of the persons listed below, they are responsible for the investigation.

Catrin Henriksson  Bertil Lindahl
Reg. Nurse  Asst. Professor, MD
Uppsala Clinical Research Centre  Uppsala Clinical Research Centre
Uppsala University Hospital  Uppsala University Hospital
Telephone 018-611 95 13  Telephone 018-611 00 00
## Supplement 2: EQ-5D

<table>
<thead>
<tr>
<th>Your own health state today</th>
<th>Your own health state today</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mobility</strong></td>
<td><strong>Best imaginable health state</strong></td>
</tr>
<tr>
<td>I have no problems in walking about</td>
<td>100</td>
</tr>
<tr>
<td>I have some problems in walking about</td>
<td>97</td>
</tr>
<tr>
<td>I am confined to bed</td>
<td>86</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td><strong>Worst imaginable health state</strong></td>
</tr>
<tr>
<td>I have no problems with self-care</td>
<td>1</td>
</tr>
<tr>
<td>I have some problems washing and dressing myself</td>
<td>6</td>
</tr>
<tr>
<td>I am unable to wash and dress myself</td>
<td>2</td>
</tr>
<tr>
<td><strong>Usual activities</strong> (eg. work, study, housework, family or leisure activities)</td>
<td><strong>Your own health state today</strong></td>
</tr>
<tr>
<td>I have no problems with performing my usual activities</td>
<td>10</td>
</tr>
<tr>
<td>I have some problems with performing my usual activities</td>
<td>7</td>
</tr>
<tr>
<td>I am unable to perform my usual activities</td>
<td>2</td>
</tr>
<tr>
<td><strong>Pain/discomfort</strong></td>
<td><strong>Your own health state today</strong></td>
</tr>
<tr>
<td>I have no pain or discomfort</td>
<td>10</td>
</tr>
<tr>
<td>I have moderate pain or discomfort</td>
<td>7</td>
</tr>
<tr>
<td>I have extreme pain or discomfort</td>
<td>2</td>
</tr>
<tr>
<td><strong>Anxiety/depression</strong></td>
<td><strong>Your own health state today</strong></td>
</tr>
<tr>
<td>I am not anxious or depressed</td>
<td>10</td>
</tr>
<tr>
<td>I am moderately anxious or depressed</td>
<td>7</td>
</tr>
<tr>
<td>I am extremely anxious or depressed</td>
<td>2</td>
</tr>
</tbody>
</table>
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