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Afflicted by an Acute Myocardial Infarction

– patients' thoughts, feelings and actions prior to care-seeking

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THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

Introduction: Acute myocardial infarction (AMI) is the most prevalent cause of death in Europe. The primary aim of early medical contact when afflicted by an AMI is to be able to treat fatal arrhythmias and to save heart muscle and thereby decreasing morbidity and mortality. In Sweden, the delay from symptom onset to medical treatment has decreased over time, with a current median delay time of 170 min. This means that almost half of the patients have a longer delay than three hours. Huge efforts to improve pre-hospital care have been performed. However, the initial patient delay seems hard to counteract.

Aim: The overall aim of this thesis was to increase the knowledge of patients' behavioural responses that may influence the decision to seek medical care when afflicted by an acute myocardial infarction.

Methods: Studies I and II have a qualitative design using focus group discussions and semi-structured individual interviews respectively as data collection methods. The analysis of the group discussion data was conducted using a theoretical model – the Self-Regulatory Model of illness behaviour. The interview data was analysed using qualitative content analysis. Study III had a cross-sectional design with development and psychometric testing of the Patients' Appraisal, emotions and action tendencies (PA-AMI) questionnaire. The questionnaire was validated using exploratory factor analysis and principal component analysis. Study IV had a cross-sectional design using the developed questionnaire (PA-AMI) as data collection method. The impact of the subscales and individual items on patient delay was analysed by Projection to Latent Structures (PLS) regression.

Results: Study I showed that patients had difficulty in clarifying the exact time point of symptom onset. A pertinent shift in appraisal was identified, the turning point, when the patients change from self-regulative illness behaviour to care-seeking. This shift seems to be affected by several partly contradictory influences and it takes a considerable time for the patients to reach this point. Study II showed that patients' emotional reactions are important and may influence the patients' pre-hospital behaviour. Study III showed satisfactory psychometric properties of the PA-AMI questionnaire. Three core dimensions emerged: 'symptom appraisal', 'perceived inability to act' and 'autonomy preservation'. In study IV, the subscales 'symptom appraisal' and 'perceived inability to act' and their items had a major influence on patient delay.

Conclusions: The thesis contributes with knowledge on the influence of patients' appraisal of symptoms and behavioural responses on patient delay when afflicted by an AMI. It is important that this knowledge should be used in the primary and secondary prevention of patients with risk for, or an already manifest coronary heart disease. An altering in patients' behavioural response when afflicted by an AMI should have a great potential to reduce patient delay and thereby reduce heart muscle loss and mortality.

LIST OF SCIENTIFIC PAPERS

- I. Nymark C, Mattiasson A-C, Henriksson P, Kiessling A. The turning point: from self-regulative illness behaviour to care-seeking in patients with an acute myocardial infarction. *J Clin Nur* 2009; 18:3358-3365.
- II. Nymark C, Mattiasson A-C, Henriksson P, Kiessling A. Emotions delay care-seeking in patients with an acute myocardial infarction. *Eur J Cardiovasc Nurs* 2014;13(1):41-47.
- III. Nymark C, Saboonchi F, Mattiasson A-C, Henriksson P, Kiessling A. Development and validation of an instrument to assess patients' appraisal, emotions and action tendencies preceding care-seeking in acute myocardial infarction – The PA-AMI questionnaire. *Submitted*.
- IV. Nymark C, Henriksson P, Mattiasson A-C, Saboonchi F, Kiessling A. Influence of symptom appraisal and ability to act on patient delay when afflicted by an acute myocardial infarction. *Manuscript*.

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LIST OF ABBREVIATIONS

AMI	Acute Myocardial Infarction
ED	Emergency Department
ECG	Electrocardiogram
EFA	Exploratory Factor Analysis
FGD	Focus Group Discussions
NIPALS	Non-linear Iterative PArtial Least Squares
NSTEMI	Non-ST segment Elevation Myocardial Infarction
PA-AMI	Patients' Appraisal, emotions and action tendencies prior to care-seeking when afflicted by an AMI
PCA	Principal Component Analysis
PCI	Percutaneous Coronary Intervention
PLS	Projection to Latent Structures
PLS-DA	Projection to Latent Structures – Discriminant Analysis
SD	Standard Deviation
SRM	Self-regulative Model of illness behaviour
STEMI	ST segment Elevation Myocardial Infarction
TAP	Think-Aloud Protocol
VIN	Variable INfluence
VIP	Variables of Importance for the Projection

INTRODUCTION

This thesis is about patients afflicted by an acute myocardial infarction (AMI) and their thoughts, feelings and actions prior to care-seeking. It is based on three empirical studies and one methodological study. I have worked as a nurse at the coronary care unit at Danderyd Hospital since 1998. In my work I have met patients expressing for example thoughts that AMI happens to others and many did not realise that their discomfort indicated a serious problem. Other patients thought they were too young to get a 'heart attack'.

When I got the opportunity to perform research about patients afflicted by an AMI I thought about why they delayed seeking medical care. Today, information about symptoms is easily accessible. There is information on the internet and from pharmacies, hospitals, health care centres and health care call centres. Also, ambulances and emergency rooms are easily accessible, depending on the place of residence. Furthermore patients with symptoms of an AMI are prioritized, both when calling the health care call centre and when arriving at the emergency room.

To be afflicted by an AMI may imply being overwhelmed with thoughts and feelings due to the discomfort being experienced. Hopefully, these thoughts and feelings force the patients to seek medical care. But until the decision to seek medical care is taken, the symptoms may cause patients trouble and worries, and they may not know which actions to take.

The delay from patient's symptom onset to seeking medical care is still far too long, and morbidity and mortality may be reduced if this time could be shortened.

BACKGROUND

Incidence and risk factors

Worldwide, AMI is the most prevalent cause of death (1). The European Society of Cardiology guidelines suggest that every sixth male and every seventh woman in Europe will die due to an AMI (2). In Sweden during 2013, the incidence of AMI was approximately 29 400 annually (3) and 6200 persons died with AMI as the underlying mortality cause.

Many of these deaths occur early during the first few hours after symptom onset. In Sweden 2013, among 5600 persons that died the same day as the AMI was registered, 93 % died outside of hospital (3). Another study from Sweden showed that of all deaths related to a first-ever major coronary event, almost 80 % occurred as an outside of hospital death between

2003-2006 (4). In spite of a continuous decrease in mortality during hospital stay (5) the out of hospital mortality remains high in patients with AMI (4).

The most important risk factors among patients afflicted by an AMI, are smoking and hyperlipidemia, psychosocial factors (depression and stress), abdominal obesity, diabetes and hypertension (6).

Definition of acute myocardial infarction

AMI is defined as myocardial cell death due to prolonged ischemia (7).

The diagnosis criteria of AMI include the detection of a rise and/or fall of cardiac biomarker values and one of the following criteria (7): symptoms of ischemia; electrocardiogram (ECG) changes indicative of new ischemia; and/or imaging evidence of new loss of myocardium or new wall regional motion abnormality.

Subclasses of acute myocardial infarction

Acute myocardial infarction can be divided into ST-segment elevation myocardial infarction (STEMI) and non-ST segment elevation myocardial infarction (NSTEMI). According to SWEDEHEART registry data from 2013 patients with STEMI have a higher short-term mortality than patients with NSTEMI (8). But over time, patients with NSTEMI have a slightly poorer prognosis than patients with STEMI. NSTEMI represents 64 % of the AMI incidence in Sweden (8).

Symptoms of acute myocardial infarction

Guidelines state that symptoms of myocardial ischemia includes various combinations of chest; upper extremity; mandibular or epigastric discomfort (7). The most common symptom of an AMI is described as pain or discomfort in the chest with various combinations of additional symptoms (9-13). Additionally, symptoms can include ischaemic equivalents such as dyspnoea or fatigue. Further symptoms may be diaphoresis, nausea or syncope. The discomfort usually lasts over 20 minutes and is often diffuse and not localized or positional or affected by movement of the region.

There is no consensus on whether men or women experience different symptoms when afflicted by an AMI, but some studies have shown that women are more likely than men to experience greater numbers of atypical AMI symptoms such as nausea, dizziness, fatigue, sweating, indigestion and numbness in the hands and palpitations (12-15). However, another

study was unable to show any gender differences in patients' symptoms although women were more likely to report a greater number of symptoms (9).

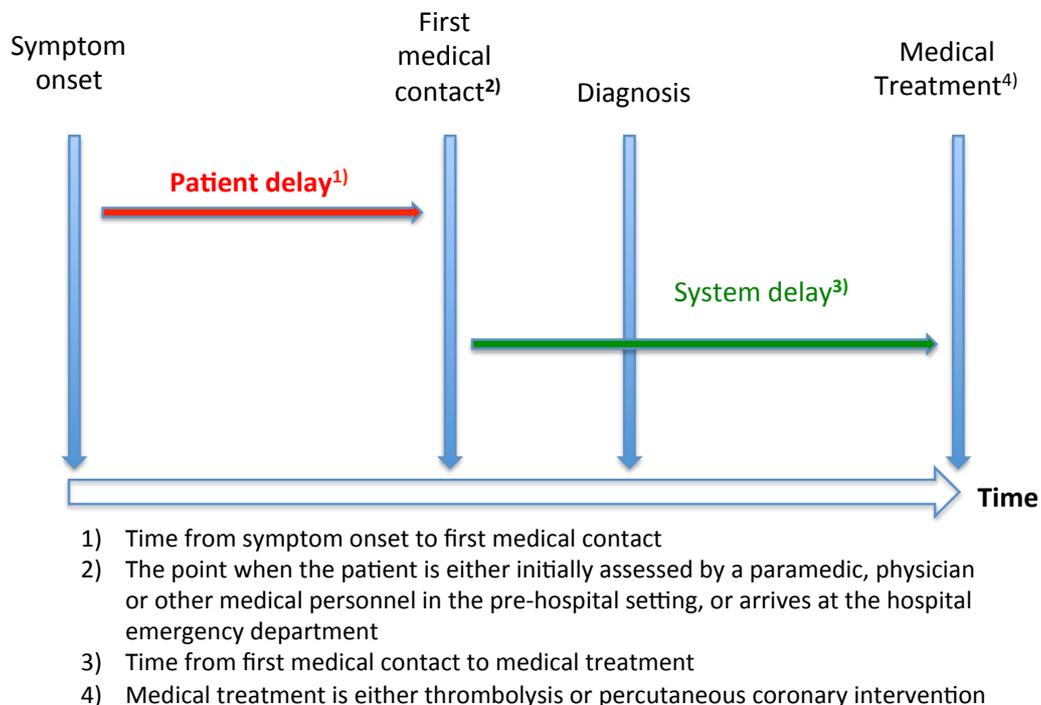
One study examined whether there were differences in symptoms between patients with STEMI and NSTEMI. In the NSTEMI group 44% of the patients had no chest pain/discomfort versus 27% in the STEMI group (16).

Patient delay in acute myocardial infarction

Definition

In studies on patients afflicted by an AMI, several definitions have been used to define delay (2). Patient delay as defined by the European Society of Cardiology is the time between symptom onset and first medical contact. The first medical contact is defined as the point when the patient is either initially assessed by a paramedic, physician or other medical personnel in the pre-hospital setting, or arrives at the hospital emergency department (2). An overview of different delay measures is presented in figure 1.

Figure 1. Overview of delay measures when afflicted by an AMI



Patient delay

In Sweden, the delay from symptom onset to medical treatment - thrombolysis or percutaneous coronary intervention (PCI) - has decreased in the last few decades with a median delay of 170 min in 2013 (8). However, it should be noted that this means that almost half of the patients experience a longer delay than three hours. The REACT trial showed a median delay of 140 min from symptom onset to hospital arrival for patients with chest pain (17). Another study in Ireland showed a median time of four hours from symptom onset to arrival at hospital (18).

The findings are inconsistent on patient delay in relation to gender and age. Studies have shown that older age groups and women have a longer delay from symptom onset to care-seeking (12, 19-21). A study by Johansson et al. found that female gender but not age prolonged delay (22). In contrast, other studies have found no such relations (10, 23-25).

Symptom perception and emotions prior to care-seeking

Patients afflicted by an AMI may perceive their symptoms as a non-severe discomfort (22, 24-27). Gradual onset of symptoms or intermittent symptoms are associated with longer patient delay (28, 29). These symptoms make it more difficult for patients to attribute their symptoms to be of a cardiac origin, which may delay care-seeking.

To experience symptoms of AMI is accompanied by subjective emotions. Fear is a common emotional reaction when thinking of the consequences that might follow if one seek medical care (30, 31). Patients may experience a fear of dying when facing the discomfort of an AMI (32-34).

Embarrassment may contribute to delay. Studies have shown that patients delayed because they were embarrassed to get help (29, 30). Qualitative studies have described patients as feeling embarrassed in front of physicians and/or ambulance staff if they had not been ill enough to seek medical care (35) or if the alarm would turn to be false (36). Moreover, patients feared being viewed as anxious or hypochondriacs in front of physicians (37), which delayed their care-seeking. Anxiety linked to the experienced symptoms may contribute to delay but also to seeking medical care more rapidly (37-39).

Behavioural response in relation to patient delay

When afflicted by an AMI the patient's behavioural response to the symptoms may have an impact on the delay in care-seeking. Patients who visit a general practitioner, or take medication when experiencing symptoms of an AMI have a significantly longer delay than

others (23, 28, 40). As well as consulting a spouse/someone else and perceiving the symptoms as tiring, lead to delay in seeking medical care (22, 23, 41, 42). Moreover, trying not to think about the symptoms, convincing oneself and others that the symptoms are not serious, resting or using home remedies contribute to delay (26, 40, 41).

THEORETICAL FRAMEWORK

Theory of appraisal

The theory of appraisal (43) provides a broad account of response to internal and external stressors. Cognitive appraisal can be understood as the process by which a person evaluates the significance of an event for his or her well-being (43). That is, when a person experiences a potentially stressful event, the subjective interpretation and evaluation of this event determine the emotional and psychological responses.

Cognitive appraisal is viewed as subdivided into three more specific forms of appraisal. First, *primary appraisal* where an environmental situation is regarded as either being positive, stressful or irrelevant to well-being. *Secondary appraisal* is the subjective evaluation of the individual's own resources that are deemed available in order to cope with the event. Third, is *re-appraisal*, which refers to changes in appraisal on the basis of new information that stems from monitoring the environment and the coping efforts that are used. In *re-appraisal*, the primary and secondary appraisals may be modified if necessary.

The self-regulatory model of illness behaviour

The self-regulatory model of illness behaviour (SRM) maybe viewed as an application of appraisal theory to illness behaviour.

Patients' symptom perception, emotions, coping and appraisal can be understood in the context of the theoretical model: the Self-Regulatory Model of illness behaviour (44-46). SRM suggests that health-related behaviours and coping response are influenced by the patients' own beliefs or representations of illness. The three components of the model, interpretation of a health threat, coping strategies and appraisal, are interrelated and continue until the normal state of health is re-established. In the component *interpretation of the health threat* the health threat is assessed through symptom perceptions and social messages, i.e. seeking and/or getting information from others. In the component *coping strategies*, the patient will develop and identify a suitable coping strategy in an attempt to return to the state of health. Any coping strategy has to relate to both the illness cognition and the emotional state of the patient. In the component *appraisal* the patient determines whether to continue

with the same coping strategy, or to adopt an alternative coping strategy. Also, the interpretation of a health threat will result in changes in the emotional response. Emotional reactions may be evoked at any of the SRM stages and the model suggests that additional coping strategies and a modification of appraisal may be generated to control the emotions (47).

RATIONALE

Early care-seeking is crucial for saving patients' lives and minimizing the myocardial damage. In spite of a continuous decrease in mortality during hospital stays, the out of hospital mortality remains high. One reason is that the patient delay is still long for patients with an AMI.

Much research has been performed on typical and atypical symptoms and on symptom perception when afflicted by an AMI. However, there is little knowledge about appraisal and behavioural response in relation to patient delay.

Enhanced knowledge of factors that may influence a patient's decision to seek medical care when afflicted by an AMI is of great importance for efforts to decrease out of hospital mortality.

AIMS OF THE THESIS

Overall aim

The overall aim of this thesis was to increase the knowledge of patients' behavioural responses that may influence the decision to seek medical care when afflicted by an acute myocardial infarction.

Specific aims

I. To describe the care-seeking process from interpretation of an initial symptom to the decision to seek medical care in patients with an acute myocardial infarction.

II. To add a deeper understanding of patients' thoughts, feelings and actions that preceded the decision to seek medical care when afflicted by an acute myocardial infarction.

III. To develop and validate a questionnaire aimed to assess patients' appraisal, emotions and action tendencies when afflicted by an acute myocardial infarction.

IV. To examine if and how the appraisal processes influence patient delay and whether it is possible to discriminate between patients experiencing long and short delay as regards the decision to seek medical care when afflicted by an acute myocardial infarction.

THE STUDIES

Based on the overall aim a qualitative descriptive design was chosen for studies I and II. Themes generated in study II were then used in study III to develop and validate a new questionnaire aimed at assessing patients' appraisal, emotions and action tendencies when afflicted by an AMI. In study IV this questionnaire was applied in a survey to examine if and how the patients' appraisal processes related to patient delay.

A general description of the four studies is summarized below in tables 1 and 2. Each study is then described in more detail.

Table 1. Overview of the studies

	Study I	Study II	Study III	Study IV
Design	Qualitative descriptive design	Qualitative descriptive design	Cross-sectional design	Cross-sectional survey
Data collection	Focus group discussions	Qualitative individual interviews	Questionnaire	Questionnaire
Inclusion criteria	Treated for a first or second AMI ¹⁾ Patient delay <3 hours or > 8 hours Ability to speak and understand the Swedish language	Treated for their first or second AMI Ability to speak and understand the Swedish language	Treated for their first or second AMI Ability to speak and understand the Swedish language	Treated for a first or second AMI Ability to speak and understand the Swedish language
Exclusion criteria	Clinically unstable patients Cognitive problems	Clinically unstable patients Cognitive problems	Clinically unstable patients Cognitive problems	Clinically unstable patients Cognitive problems
Sampling	Criterion sampling	Criterion sampling	Consecutive sampling	Consecutive sampling
Study period	October 2005 - March 2006	February 2008 - May 2008	May 2011 - September 2012	November 2011 - August 2014
Sample size	5 focus group discussions (15 patients)	14 patients	124 patients (28 in the pre-test and 96 in the psychometric testing)	326 patients
Females	7 (47%)	4 (29%)	30 (26%)	84 (26%)
Age mean (range)	63 (40-74)	62 (39-86)	64 (38-91)	66 (35-94)

¹⁾ Acute Myocardial Infarction (AMI).

Table 2. Analyses performed in included studies

Analysis	Study I	Study II	Study III	Study IV
Qualitative content analysis	X ¹⁾	X		
Descriptive statistics	X	X	X	X
Paired sample t-tests			X	
EFA ²⁾			X	
PCA ³⁾			X	
Cronbach's alpha			X	
Independent t-tests			X	X
Multivariate regression analyses (PLS;PLS-DA) ⁴⁾				X

1) In study I, deductive and inductive content analyses were used. 2) Exploratory Factor Analysis (EFA). 3) Principal Component Analysis (PCA). 4) Projection to Latent Structures (PLS) regression analysis respectively PLS-Discriminant Analysis (DA).

Ethical considerations

The studies followed the principles outlined in the ‘Declaration of Helsinki; 1964’ and were approved by the Regional Ethical Review Board, in Stockholm, Sweden (Study I and II Dnr 2005/933-31, study III and IV Dnr 2011/716-31/1). Overall, the patients in the studies were informed orally and in writing about the study they would take part in. All patients gave their written informed consent to participate and were free to withdraw at any time without giving a reason.

To ask patients to speak in a group about a possible life-threatening cardiac event is a task of great complexity. The discussions may recall unpleasant memories and eventual remorse about how they had handled the situation. On the other hand interviews can be seen as relieving. Also, qualitative interviews can be considered as intrusive as the informants may have to share thoughts and experiences that perhaps they do not want to share (48). Patients who had further questions or worries about their cardiac event were able to ask questions to the moderator/interviewer in studies I and II. Also, patients in all studies were given

telephone numbers to allow them to contact the research group about the studies. However, none of the patients used these opportunities.

Study I

The turning point: from self-regulative illness behaviour to care-seeking in patients with an acute myocardial infarction

Methods

Design

A qualitative descriptive design was chosen to generate knowledge on the interpretation of an initial symptom to the decision to seek medical care in patients with an acute myocardial infarction. This design recognises that reality is complex and subjective and a person has his/her unique experiences of illness (48). Focus group discussions (FGD) were chosen for the data collection where the patients could consider their own views in the context of others (48, 49). In the FGD concentrating on the study aim and a small number of topics created a focussed discussion among the participants in the groups (48, 49).

Sample and procedure

Based on criterion sampling, i.e. choosing patients being treated for their first or second AMI and who had sought medical care within three or after eight hours from initial symptom onset as indicated in the patient's record, eight men and seven women, 40-74 years old (median 63 years) were included. They spoke and understood the Swedish language and were willing to participate. Clinically unstable patients and/or those with cognitive problems were excluded. The patients that fulfilled the inclusion criteria were consecutively invited to participate by the first author three to five days after admission to the hospital. Information about the study was given orally and in writing. Within two weeks after discharge from the hospital, a time for participation was agreed upon during a telephone call.

Data collection

The patients were divided into groups based on gender and patient delay. In total, five FGDs with three to four participants in each group were completed. The number of FGDs was determined by when repetitive data was achieved. In one group there were only two participants because one reported sick. An interview guide was followed to keep the interactions focused while allowing individual perspectives and experiences to emerge. Each discussion started with an opening question 'Please tell me about the first signs you noticed

when you had your AMI'. The discussions were tape-recorded and lasted for one to nearly two hours. A moderator (the first author) guided the discussions.

The process of analysis

First, the transcripts were listened through and transcribed verbatim by the first author. Then, the tapes were listened through simultaneously while reading the transcripts. The text was read several times to gain a sense of the whole. Inspired by the self-regulatory model of illness behaviour (SRM), text units, i.e. strings of words, a sentence or several sentences bound together by their content were identified and categorised within the SRM (44-46). Furthermore, the data that did not fit into the model were analysed based on the principles of content analysis.

Main results

When afflicted by an AMI, patients had difficulty interpreting their symptoms and they tried different coping strategies in the hope that the symptoms would wane. They evaluated whether to continue with their coping strategy or adopt an alternative.

In the first stage, '**interpretation of the health threat**', the patients' '*symptom perception*' was described as various combinations of discomfort. The pain differed in intensity, localisation and duration both over time and between patients. '*Social messages - seeking and getting information from others*' described how information of plausible causes was sought from medical authorities such as the health care centre, the health care call centre or the pharmacy. '*Representation of the health threat*' implied the 'identity of the illness and its causes'. Patients described difficulties in understanding and interpreting the discomfort and distinguish between discomfort and more serious illness. Further representation of the health threat could be described as 'consequences, time-line and cure/control of the illness'. In '*emotional response to the health threat*' there were descriptions depicting signs of anxiety, fear and nervousness in relation to experienced symptoms. These emotions influenced patients' behaviour and were also described as frightening e.g. when the pain intensity continued and did not decrease.

In the second stage, '**coping strategies**', patients used different strategies in an attempt to return to the state of health including '*approach coping*' i.e. 'self-care of the illness'. Patients tried various self-care strategies in the hope that the symptoms would ease, such as lying down, going for a walk and/or ingesting analgesics. '*Interaction with others*' was understood as talking to others with the purpose of sharing their problems rather than getting advice to

seek care. *'Avoidance coping'* was described as 'wishful thinking and denial' exemplified by patients attributing the symptoms to harmless causes such as a back-pack or a tick bite and thoughts that the symptoms would pass. *'Avoiding talking about the health threat and avoiding seeking medical care'* was described as patients avoided talking about the health threat as they emphasized they did not want to worry and trouble others. They avoided seeking medical care as they thought the symptoms were not severe enough.

In the third stage, **'appraisal'**, patients determined whether to *'continue or adopt an alternative coping strategy'* when the symptoms increased, remained or new symptoms appeared. It was both difficult and time-consuming for them to alter their strategy. *'The turning point: from self-regulatory behaviour to care-seeking'* was defined as when the patient lost or abandoned the self-control of the health threat and decided to seek medical care, or let someone else decide for them. This shift was based more on vague feelings of an incapability of comprehending and handling the situation as a whole due to a persisting and/or increasing sense of illness, discomfort or pain.

In sum, this study addressed the care-seeking process from interpretations of an initial symptom to the decision to seek medical care. There were difficulties in clarifying the exact point of onset of symptoms. The turning point, when the patient changed from self-regulative illness behaviour to care-seeking, seemed to be affected by several partly contradictory influences and it took a considerable time for the patients to reach this stage.

Study II

Emotions delay care-seeking in patients with an acute myocardial infarction

Methods

Design

The study had a qualitative descriptive design using individual semi-structured interviews (48). The method was chosen with the purpose of gaining a more detailed perspective on the interviewed persons' thoughts, feelings and actions that preceded the decision to seek medical care when afflicted by an AMI.

Sample and procedure

Based on criterion sampling, ten men and four women, 39-86 years old, were included in the study. The selected patients were being treated for a first or second AMI. The patients spoke

and understood the Swedish language and were willing to participate. Clinically unstable patients and/or those with cognitive problems were excluded. The patients were invited to participate by the first author, 3-5 days after admission to hospital. They received both written and verbal information about the study.

Data collection

An interview guide, with four main questions, was used to ensure that the same basic lines of inquiry were pursued with each interviewed person. The interviews began with the opening question 'Please tell me about the first signs you noticed when you had your AMI'. The following questions were designed to probe the patient's thoughts, feelings and actions from symptom onset to the decision to seek medical care. The interviews took place in a neutral setting in the hospital where the participants could feel comfortable.

Data Analysis

A qualitative content analysis was used (50) to analyse the data with the purpose of interpreting the underlying meaning of the text.

First, the tapes were listened through and transcribed verbatim by the first author and then they were listened through while reading the transcripts. Sentences or paragraphs containing issues related to each other through their content and context (i.e. meaning units) were identified and extracted from the text. Each meaning unit was condensed and labelled with a code. The codes that appeared to belong together were placed in groups and preliminary sub-themes were formed. Connections between sub-themes were sought while searching for themes on a more abstract, interpretative level.

Main results

Four themes were conceptualized describing patients' thoughts, feelings and actions that preceded their decision to seek medical care: *'being incapacitated by fear, anguish and powerlessness'*, *'being ashamed of oneself'*, *'fear of losing a healthy identity'* and *'striving to avoid fear by not interacting with others'*.

The theme *'being incapacitated by fear, anguish and powerlessness'* was described with the sub-themes *'weakened by fear and anguish'* and *'feelings of despair and powerlessness'*. Patients feared having a serious or dangerous disease. Also, they felt an intense or increased anguish when the discomfort was severe or did not disappear. The patients expressed feelings

of despair and powerlessness when they did not know how to contact health care services or were unable to contact their general practitioner.

The theme ***'being ashamed of oneself'*** was described with the sub-themes *'hesitation to cross a boundary'*, *'feelings of failure'* and *'feelings of being exposed'*. Patients expressed hesitation to cross a boundary, for example, they did not know how ill they should feel before seeking medical care. They felt uncertainty about whether to call an ambulance or not, because it might later turn out that they had not needed it. Others said they were too proud to seek medical care and forced themselves to do so. Also, they experienced feelings of being exposed, such as embarrassment, if an ambulance might pick them up unnecessarily, or if neighbours might see them in a vulnerable situation.

The theme ***'fear of losing a healthy identity'*** was described with the subthemes *'struggling to hold on to their self-image'*, *'labelling their discomfort with unthreatening explanations'* and *'avoiding dependency on their discomfort'*. Patients struggled to hold on to their self-image as a healthy person. They were convinced that an AMI could not happen to them. They tried to overcome the persistent discomfort by labelling it with unthreatening explanations.

The theme ***'striving to avoid fear by not interacting with others'*** was described with the sub-themes *'trying to protect others'* and *'hesitation to follow advice to seek medical care'*. The patients did not want to bother or frighten their spouses, friends or colleagues with their discomfort as they thought others had enough problems with their own everyday lives. There was a hesitation to follow advice by health professionals at the health care centre to go to the emergency room, as the patients were not accustomed to emergency care professionals or the health care system.

In sum, the study indicates that emotions are important when experiencing the discomfort of an AMI. These emotions were full of inconsistencies and may partly explain the undesired and persisting long patient delay in the care-seeking process.

Study III

Development and validation of an instrument to assess patients' appraisal, emotions and action tendencies in acute myocardial infarction – the PA-AMI questionnaire

Methods

Design

A cross-sectional design with development and psychometric testing of a questionnaire to assess patients' appraisal, emotions and action tendencies prior to care-seeking in AMI.

Sample

The eligible patients were being treated for their first or second AMI. The patients spoke and understood the Swedish language and were willing to participate. Clinically unstable patients and/or those with cognitive problems were excluded. In total, 124 patients were included and 28 of these participated in the pre-test of the item pool. The remaining patients participated in the examination of the construct validity of the questionnaire.

Procedure

An item pool was generated based on themes conceptualized in our foregoing qualitative study (study II). The generated items were conceptually divided into two parts. Part I consisted of situation-specific items regarding patients' thoughts, feelings and behaviour prior to care-seeking when afflicted by an AMI. Part II consisted of items about personal behavioural tendencies in general with relevance to the care-seeking decision. All items were to be answered on a Likert-type rating scale with six grades from 1='do not agree at all' to 6='totally agree'.

The preliminary item pool was first examined using a cognitive interviewing approach i.e. the 'Think-Aloud' Protocol (TAP) (51), to assess the usability of the items. Nine patients were individually interviewed while still in hospital and being treated for a suspected AMI.

Then a test-retest analysis at item level was performed. Twenty-nine patients were included. The retest questionnaire was mailed by post to the patients after two weeks and was completed and returned by 19 patients.

Finally, the research group examined the remaining items in regard to comprehensibility and to ensure coverage of target variables, and then the questionnaire was administered to 96 patients.

Data analysis

Paired sample t-tests were conducted to evaluate the stability of item response over time in the test-retest analysis. Descriptive statistics were employed for patient demographic and clinical characteristic data.

An Explorative Factor Analysis (EFA) with a principal factor extraction method was performed to detect the underlying factor structure of the items in the two parts of the questionnaire. Varimax rotation was used to extract the factors with the assumption that putative sub-scales were independent of each other. A loading level of more than 0.3 was chosen for the items to be included in a factor. To further test the robustness of the structure a Principal Component Analysis (PCA) was performed with the non-linear iterative partial least squares (NIPALS) algorithm (52). This allowed analysis of wide data matrices i.e. many variables (items) in comparison to the number of subjects.

The reliability of the scale was measured by calculation of the Cronbach's alpha coefficient for parts I and II, and for the subscales. Cronbach's alpha is a measure of internal consistency i.e. to what extent all items measure the same construct.

The statistical software IBM SPSS Statistics version 21 (IBM, US, 2012), Statistica 12 (StatSoft, Tulsa, US) and SIMCA P+[®], version 12.0.1.0, (Umetrics Ltd, Umeå, Sweden) were used for the statistical analyses.

Main results

Clinical and demographic data

Of the included 96 patients, 74% were men. The mean age was 64 years (SD 11.5). Of these, 13 % had experienced a previous AMI.

Item development

The primary generated item pool consisted of 15 items in part I, and 20 items in part II.

TAP showed that the patients comprehended all items, and could recall the necessary information, respond to the items and use the grading of the given Likert-type scaling to report their responses. Two items were modified as these contained ambiguous meanings.

The analysis of the test-retest item score distributions and central tendencies showed inadequate variability of five items (three in part I, and two in part I) as regards floor and ceiling effects. Due to this, the phrasing of these items was modified, I. The paired sample t-

tests showed no significance difference between test-retest at item level, which confirmed the stability of item responses over time.

After scrutinizing the items, four further items were added, three in part I, and one in part II, based on consensus in the research group to ensure full conceptual coverage of the target variables. This resulted in a questionnaire consisting of 18 items in part I, and 21 items in part II. An overview of the item development process is shown in Table 3.

Table 3. An overview of the item development process

Phase of procedure	Item development		
Themes	1. Being incapacitated by fear, anguish and powerlessness 2. Being ashamed of oneself 3. Fear of losing a healthy identity 4. Striving to avoid fear by not interacting with others		Research group
Conceptual understanding	Part I Situation-specific items	Part II Items about generic behavioural tendencies	Research group
Generation of an item pool	15 specific items about being afflicted by an AMI	20 items about patients' behavioural tendencies in general	Research group
Pre-test of items			
1. TAP	1. Adjustments of 1 item.	1. Adjustments of 1 item.	9 patients
2. Test-retest	2. Adjustments of 3 items.	2. Adjustments of 2 items.	19 patients
3. Scrutinizing of items	3. Three items were added.	3. One item was added.	Research group
Analysis of the final questionnaire	18 specific items about being afflicted by an AMI	21 items about patients' behavioural tendencies in general	96 patients

Factor structure and internal consistency

Factorability was confirmed by inspection of the correlation matrix and by anti-image correlations greater than 0.5. Due to low communalities and to cross loading in two factors, the number of items was reduced by three in part I. The EFA resulted in a two-factor model that explained 59.3% of the variance. The first factor was labelled '*symptom appraisal*' and dealt with the seriousness of the symptoms and urgency of seeking medical care. The second

factor was labelled '*perceived inability to act*' as it dealt with perceived loss of control and ability to act.

Factor loadings of items in part I of the questionnaire are shown in table 4.

Table 4. Factor loadings of items in part I of the questionnaire

Items	Factor 1	Factor 2	Communality
It took me a long time to realize that the symptoms were serious.	.81		.73
I thought the symptoms would pass.	.74		.64
I tried to divert my thoughts from the symptoms/discomfort.	.64		.50
I tried different ways to reduce my symptoms (e.g. medication, eat, rest).	.65		.51
I thought the symptoms were caused by something else than a heart attack.	.69		.58
I got completely powerless to act when I got my symptoms.		.60	.47
I did not know what to do when I got my symptoms.	.41	.72	.69
My symptoms paralyzed me.		.85	.71
It felt as I lost control over myself when I got my symptoms.		.80	.71
I did not think my symptoms were serious enough to seek the emergency care.	.83		.72
It was difficult to decide seeking care for my symptoms	.81		.73
I felt unsure where to turn to for my symptoms.	.56		.54
At first, I did not want to seek care.	.76		.66
It took time to decide what to do when I got ill.	.74	.31	.70
<i>Explained variance (%)</i>	48.87	10.43	
<i>Eigenvalue</i>	6.84	1.46	
<i>Cronbach's alpha</i>	.91	.78	

Loadings < 0.3 are not displayed

In part II, seven items were excluded due to low communalities. The EFA resulted in a two-factor model, explaining 40.4 % of the variance. Only the first factor was deemed interpretable. This factor was labelled '*autonomy preservation*' and dealt with patients' efforts to restore or preserve a sense of healthy identity and autonomy. Factor loadings of items in part I of the questionnaire are shown in table 5.

Table 5. Factor loadings of items in part II of the questionnaire

Items	Factor 1	Factor 2	Communality
I nearly always feel healthy.		.55	.33
It is easy for me accept help when needed.		.48	.41
I do not want others to decide over me.	.55		.38
I do not want to trouble others by telling them about my symptoms.	.67		.59
I do not want to be questioned by others.	.67		.55
I do not want to put the master of my fait in the hands of others.	.64		.44
I hesitate to tell others about my symptoms.	.69		.66
Everyone has enough with their own worries.	.62		.46
I have lived a healthy life.		.51	.43
I am satisfied how I spent my life until now.		.74	.52
It is very unpleasant to be questioned by others.	.59		.50
When I am ill I want to decide by my self who is going to know about it.	.69		.53
I avoid seeking medical care if it isn't anything very serious.	.46		.50
I do not want to be seen as a person who complains unnecessarily about by health.	.65		.54
<i>Explained variance (%)</i>	<i>28.91</i>	<i>11.51</i>	
<i>Eigenvalue</i>	<i>4.05</i>	<i>1.61</i>	
<i>Cronbach's alpha</i>	<i>.87</i>	<i>.48</i>	

Loadings < 0.3 are not displayed

The PCA analysis using the NIPALS algorithm confirmed the EFA analysis.

Internal consistency showed a Cronbach's alpha of 0.92 for the items in part I, and 0.79 for the items in part II.

In sum, this study describes the development of the 'PA-AMI questionnaire' to assess Patients' Appraisal, emotions and action tendencies prior to seek medical care when afflicted by an AMI. The developed questionnaire demonstrated satisfactory psychometric properties and factorial structure, which corresponded to the core dimensions in the appraisal process of patients afflicted by an AMI. The core dimensions were '*symptom appraisal*', '*perceived inability to act*' and '*autonomy preservation*'.

Study IV

Influence of symptom appraisal and ability to act on patient delay when afflicted by an acute myocardial infarction

Methods

Design

A cross-sectional survey.

Sample and procedure

Eligible patients were consecutively identified while still receiving hospital care at the coronary care unit of a large hospital in Sweden after their first or second AMI. They were invited to participate 2-5 days after admission and received both written and verbal information on the study. The patients spoke and understood the Swedish language and were willing to participate. Clinically unstable patients or those with cognitive problems were excluded.

Data collection

The patients were asked to fill out the questions in the previously described PA-AMI questionnaire, described in study III. The questionnaire included a section of questions about age, gender, county of birth, cohabiting status, educational level and employment.

Registry data

Clinical risk factors variables were obtained from SWEDEHEART, the national registry of all patients hospitalized for acute coronary syndromes in Sweden (53).

Data analysis

Descriptive data are described as means and standard deviations (SD) or 95% confidence intervals for normally distributed data and medians and interquartile ranges for non-normally distributed data. In the regression analyses non-normal and skew distributions were converted and checked to be normally distributed after log transformation. The statistical software Statistica©12 (StatSoft, Inc. Tulsa, OK, USA) was used for conventional statistical analysis.

Multivariate regression and discriminant analyses were performed by Projection to Latent Structures regression (PLS) and PLS-Discriminant Analysis (DA) respectively, using the non-linear iterative partial least squares (NIPALS) algorithm (52) that allowed the analysis of wide data matrices i.e. many variables (items) in relation to number of subjects. This meant

that in addition to the analysis based on the subscales defined in study III, we could also perform a comprehensive analysis including all items in the two parts of the questionnaire. The number of components in the PLS-DA analysis was determined by cross validation (54). The algorithm in this analysis used a decline in Q2 (the predictive validity) to determine the number of principal components to extract to avoid over-fit. Q2 was calculated by cross-validation.

Variables of Importance for the Projection (VIPs) were listed. VIP is the sum of all model dimensions of the contributions VIN (variable influence). VIPs with a value exceeding 0.8 and with a confidence interval not including zero were considered to have an influence on the projection (52, 54, 55). With multivariate methods, it is possible to investigate the relations between all variables in a single context. When fitting a Projection to Latent Structures (PLS) model, PLS finds the linear relationship between response variables and predictor variables (52, 54). The significance testing was based on an ANOVA of the cross-validated residuals (CV-ANOVA). The statistical software SIMCA P+[®], version 12.0.1.0, Umetrics Ltd, Umeå, was used.

Main results

A total of 326 patients completed and returned the questionnaire, meaning that the response rate was 80 %. However, for 20 of the patients it was not possible to calculate patient delay due to missing data. The mean age of the patients was 65 years; SD \pm 11 and 74 % of them were males. There were no significant differences with the exception of a higher proportion of patients with ST-elevation myocardial infarction (STEMI) in the short delay group.

The PLS regression with patient delay as a response variable and scores of the four subscales in the PA-AMI questionnaire, age and sex as predictor variables resulted in a one component solution. Subscale 1 –‘*symptom appraisal*’- and subscale 2 –‘*perceived inability to act*’ - had VIP values above 0.8 with confidence intervals not including zero, showing that they had an influence on the projection (CV ANOVA; $p < 0.0001$). Sex and age had no influence. In addition, PLS regression was performed with all the separate items of the PA-AMI included as potential predictors of delay. This regression was significant, showing a dominating influence of the items of the subscale ‘*symptom appraisal*’ (CV ANOVA; $p < 0.0001$).

To further analyse the discriminative power of the subscales, two PLS-Discriminant Analyses (DA) were performed on patients with a cut-off of delay at one hour respectively at 12 hours. At one hour subscale 1 – ‘*symptom appraisal*’ - had the greatest influence (CV ANOVA;

p=0.00012) in contrast to at 12 hours where subscale 2 – *'perceived inability to act'* - had the same discriminatory power as *'symptom appraisal'* (CV ANOVA; p=0.045).

In order to generate a greater contrast a PLS-DA was performed between patients in the lowest delay quartile i.e. those with the shortest delay, and those in the highest delay quartile, i.e. those with the longest delay. This resulted in a regression result with two significant independent components. The first component explained the major part of the variance with influences of the subscales *'symptom appraisal'* and *'perceived inability to act'* on the discrimination. The second significant independent component of the PLS-DA-regression indicated an independent but less pronounced impact of the two remaining subscales in PA-AMI i.e. a *'healthy identity'* and *'autonomy preservation'* (CV ANOVA; p=0.0005).

To further test the robustness of the results a logistic regression analysis was performed. This analysis confirmed that the subscales *'symptom appraisal'* and *'perceived inability to act'* had significant prognostic influences. At the short cut off between patient delay (one hour) the subscale *'symptom appraisal'* had a significant influence (p=0.0027) as opposed to at the long cut-off between patient delay (12 hours) where only the subscale *'perceived inability to act'* had a significant influence (p=0.042).

In sum, the PLS regression with patient delay as response variable and the four subscales or items in the PA-AMI questionnaire, age and sex as potential predictor variables showed that the subscales *'symptom appraisal'* and *'perceived inability to act'* and their items but not sex and age had an influence on patient delay. Further, *'symptom appraisal'* had its greatest impact at short patient delay whereas *'perceived inability to act'* had its greatest influence at long patient delay.

DISCUSSION

General discussion

Many patients still delay too long before taking the decision to seek medical care when afflicted by an AMI. In study I, patients had difficulty to clarifying the exact time point of symptom onset which may be caused by the complexity of the symptoms. Furthermore, patients' symptom experiences did not seem to match their previous expectations. Based on the results of study I a pertinent shift was defined, the turning point, when patients changed from self-regulative illness behaviour to care-seeking. This shift in appraisal and coping strategy seemed to be affected by several partly contradictory influences and it took a considerable time for many persons to reach this stage. In study II a central finding was the

importance of patients' emotional reactions and the influence these reactions may have on patients' pre-hospital behaviour. The emotions that were described by the patients were full of inconsistencies, and the experienced emotions might be an important explanation for the inappropriate long patient delay. Based on the qualitative studies I and II it was essential to further increase the knowledge about patients' behavioural responses when afflicted by an AMI. In study III a questionnaire (PA-AMI) was developed to assess patients' appraisal, emotions and action tendencies when afflicted by an AMI. Three sub scales of the PA-AMI questionnaire emerged in the analysis, namely *symptom appraisal*, *perceived inability to act* and *autonomy preservation*. The PA-AMI questionnaire was used in the cross-sectional survey in study IV, which included 326 patients. The study showed that in particular the subscales *symptom appraisal* and *perceived inability to act* and the items of these subscales had an influence on patient delay. Thus, the influence of patients' appraisal process seems to offer new possibilities for shortening the patient delay. The PA-AMI could be considered for use in educative efforts to shorten patient delay. However, the conceivable effects of even a small reduction of patient delay should have a great potential to preserve functioning heart muscle and to save patient lives.

Symptom appraisal

The subscale *symptom appraisal* addresses the patients' evaluation of the seriousness of symptoms and the urgency to seek medical care. *Symptom appraisal* was the subscale that had an influence on patient delay in all regression analyses at all cut-off times. The influence was especially pronounced compared to the other subscales when comparing patients with an extremely short delay and those with a longer delay.

The main finding of the importance of the *symptom appraisal* process should have important clinical implications. The appraisal process is a broad and complex construct with both internal and external moderators. When trying to understand and explain the influence of *symptom appraisal* on patient delay it is important to consider the complexity of the decision to seek or not to seek medical contact. This decision is based on how a person interprets him/herself in the present situation. Also how one's own beliefs and representations of illness contribute to whether the situation is considered as a health threat. This can be understood, according to Lazarus and Folkman, as primary appraisal (56). If the symptom is regarded as stressful to the patient the emotional and psychological responses are determined in accordance with the perceived health threat.

In the secondary appraisal (56), patients' subjectively evaluate their own resources and uses different available coping strategies to handle the event, such as taking medication, eating or resting. If these coping strategies are unsuccessful, patients' re-appraise and change their interpretation of the situation repetitively over time until they see their situation in a new light, reach their turning point and decide to seek medical care. Even other researchers have described a turning point when patients got new insights that help them to change behaviour patterns and cope with the demands of the disease. For example Hörnsten et al. have studied patients with diabetes and described the turning point as the integration of illness and self-management, finding strategies to control their life situation (57).

Studies have shown that patients have difficulty perceiving their discomfort as severe (22, 25-27). Further, that their experienced symptoms do not match their expectations of symptoms of an AMI (58, 59). Studies also show that patients use different coping strategies to handle the situation (23, 41). This thesis adds that the evaluation of the seriousness of symptoms and of the urgency to seek medical care is important to consider in order to understanding the patients' behaviour when afflicted by an AMI.

The patients' health-related behaviour and coping responses could be understood according to the Self-regulatory Model of illness behaviour (SRM). The three components of the model: interpretation of a health threat, coping and appraisal, interrelate and the process continues iteratively until it is deemed successful and the normal state of health is re-established (44-46). However, study I showed that some patients seemed to continue with their coping-strategies and appraisal and re-appraisal for a long time. Moreover, Walsh and colleagues described SRM as a useful theoretical model for partially explaining the patient delay. However, there are complex interactions between symptoms and patients' responses that will need to be considered (60).

Perceived inability to act

Perceived inability to act had its greatest influence on the discrimination of patients with excessively long delay and patients with shorter delay. At the one hour cut-off it had a less prominent influence on the projection. This shift over time is important to consider if we want to understand the mechanisms that explain patient delay. Given the design of the study these reasons can only be speculated on. For example patients experiencing initial symptoms may assume that the symptoms will pass, or they may try different coping strategies to get rid of the symptoms. Then with time they change their appraisal when they realise that

symptoms will not pass. For some patients, this re-appraisal may result in an inability to act rather than to seek care.

To our knowledge the construct *perceived inability to act*, i.e. to lose control over oneself, to be paralyzed by the symptoms, and to have a sense of powerlessness, and the impact of this construct on patient delay have not been studied previously. *Perceived inability to act* deals with to what extent the patients' reactions in response to these symptoms were appraised as a serious threat.

Thoughts about the aspects of a situation are associated with experienced emotions (61, 62). This means e.g. when afflicted by an AMI, emotions such as anxiety and powerlessness may be associated with thoughts about not knowing what to do, i.e. there may be an inability to act. Being anxious and powerless may also have an effect on the ability to retrieve information and to select an appropriate action strategy, such as where to seek medical care and whom to call, as found in the qualitative studies I and II. Eysenck and colleagues state that anxiety is an aversive emotional and motivational state occurring in threatening circumstances (63). Johansson and colleagues describe patients' anxiety as mainly related to the grade of the symptoms: the more severe the symptoms the more severe the anxiety (38) which might contribute to patient delay.

Autonomy preservation

Contrary to expectations, *autonomy preservation* did not stand out as an important subscale in relation to patient delay, and was only shown to evolve at the most extreme patient delays.

Autonomy preservation addresses the patients' efforts to restore or preserve a sense of a healthy identity and autonomy. The results of study III suggested that the signs and symptoms associated with an AMI were not only appraised as a serious health threat, but could also have more comprehensive implications as regards the patients' sense of identity, autonomy, and integrity.

In the qualitative studies I and II patients avoided talking to others and seeking medical care. As discussed in study III, to avoid seeking care might be an effort to prevent social disclosure of personal information that the patient may perceive as humiliating, embarrassing or stigmatizing (64).

The qualitative studies in this thesis identified feelings of embarrassment, humiliation and being ashamed. The findings about shame in study II were a novel and interesting result. Shame was also expressed in another qualitative study as patients felt ashamed of being

sick when they were afflicted by an AMI (32). The interpretation in this thesis is that shame may be an important latent component in patient delay and should be investigated more thoroughly in future studies. Shame can be experienced as painful and as difficult to describe, and evokes for example a desire to hide or flee (65).

It has been suggested that manifestations of appraisal should preferably be assessed in relation to specific stressors, rather than as generic behavioral tendencies (66). This thesis shows a broad variety of appraisal and action tendencies may appear when a person is afflicted by a possible AMI. AMI as a specific stressor can thereby be seen as having unique characteristics for each afflicted patient. Thus, during the development of the PA-AMI items, it was a challenge to construct relevant situation-specific items dealing with patients' efforts to restore or preserve a sense of a healthy identity and autonomy.

There are only a few questionnaires that are used to obtain self-reported information on patient delay and factors contributing to that delay. The Response to Symptom Questionnaire (31) addresses six domains; context; antecedents of symptoms; affective or emotional response; behavioural response; cognitive response; and response to others. The 'Acute Coronary Syndrome Response Index' is another questionnaire built on patient's knowledge, attitudes and beliefs regarding the acute coronary syndrome and how these influence delay in response to early symptoms (67). Another questionnaire that is used in Sweden was designed to obtain information about patient delay and factors contributing to this delay in patients admitted to a coronary care unit due to suspected AMI (22). This questionnaire included items in four domains; baseline characteristics, symptoms, course of event and means of transport to the hospital. Also, Thuresson and colleagues (68) used a modification of this questionnaire. However, none of these questionnaires tap the appraisal process related to patients' emotions and action tendencies when afflicted by an AMI.

It is important to reflect on how the increased knowledge gained in this thesis can be implemented in health care settings and in public health strategies. There are limited numbers of intervention studies aimed to shorten patient delay. Most of the interventions have focused on media campaigns aiming to make the patients aware of AMI symptoms and stressing the importance of early medical contact (17, 69). However a review scrutinizing these studies summarise that they failed to show an effect on patient delay (70). Two randomised controlled trials with individualised patient education on delay, based partly on the SRM model, have been published (18, 71). One showed a reduction of patient delay at follow-up of two years (18). The study was designed to affect behavioural changes in the presence of symptoms of acute coronary syndromes. For example, the patients were supported to inform

another person when perceiving symptoms of an AMI. The other using a similar concept failed to show a reduced delay (71). This thesis adds that it should be of importance to also consider the patients' symptom appraisal and their behavioural tendencies prior to care-seeking in future patient educations, and also in continuous medical education of health care personnel, meeting patients with a high risk of, or an already identified coronary heart disease.

Methodological considerations

Patient delay is a complex phenomenon. To increase knowledge about patients' behavioural response when afflicted by an AMI, both qualitative and quantitative methods were used. A qualitative descriptive design was used in studies I and II with focus group discussions (FGD) as the data collection method in study I, followed by individual qualitative interviews in study II. In study III a questionnaire was developed and psychometrically tested based on the findings of the qualitative studies. Study IV was a cross-sectional survey to evaluate the influence of behavioural response on patient delay using the developed questionnaire in study III.

The qualitative studies

The sampling procedure in studies I and II was purposive in order to capture variations of patients' experiences and thus maximize data of the studied phenomenon and reach representative trustworthiness (48). The methods used recognised that reality is subjective and that a person has his/her own unique experiences of illness (48). In both studies I and II there were predetermined criteria i.e. men and women of different ages and with differences in patient delay.

Qualitative research design is flexible (72) and the number of participants in studies I and II was not decided upon beforehand. After five FGDs the data seemed to be repetitive. In total, eight men and seven women participated with three to four participants in each group. In one group there were only two participants because one called in sick. In the literature on FGD there are different opinions on how many participants there should be in a group to have a reflective discussion (48, 73). However, the discussion between the two participants went well and provided rich descriptions of their experiences. After four FGDs in study I, data seemed to be repetitive but an additional interview was conducted to validate the data collection. A strength was that the same person (the author of this thesis) performed the data

collection process in the studies I and II. The data was collected in near time to the patients' experiences in an effort to reduce recall bias, which contributed to trustworthiness.

To seek agreement i.e. validation among co-researchers to reach credibility is questionable according to Sandelowski (74) because multiple realities exist that are dependent on subjective interpretations. On the other hand, Patton discusses whether it could be valuable for multiple persons to analyse the same data (48). In study I and II the first author conducted the process of reading, re-reading and preliminary categorisation. The preliminary coding was followed by discussions in the research team resulting in a shared understanding and an agreement on the coding.

Credibility also deals with how well research findings cover data. Representative authentic quotations from the transcribed text were selected to illuminate the findings in studies I and II.

Trustworthiness includes the question of transferability, which means that results could be transferred to other patients in similar situations/context (50). To improve the judgment of transferability, the data collection and analysis process were carefully described.

Determining whether the results are transferable to another context (or not) rests with the readers (50). The findings might, in the right context, be transferrable to similar groups of patients afflicted by an AMI.

The quantitative studies

The research group developed the items and examined whether the content of the items covered all aspects of the themes in study II to ensure the content validity of the questionnaire. Cognitive interviewing was used to assess the usability of the questionnaire. The construct validity of the questionnaire was examined through factor analysis i.e. EFA and PCA. Furthermore, study III had an explorative design and there were no other instruments for establishing convergent validity of the assessed dimensions.

Patients in studies III and IV answered the questionnaire in retrospect, which might have introduced recall bias. However, within three days the study nurse (the author of the thesis) gave the patients the questionnaire. Thereafter, the patients had time to reflect upon their situation when the acute phase of the AMI had passed. The same study nurse performed the inclusion of all patients.

A limitation of all studies is the potential, but inevitable, bias that data are absent from patients who have died or who were too ill to participate in the study. A further limitation of the external validity is that the questionnaire was only in the Swedish language, which excluded patients who did not understand Swedish. However, 17% of the patients that responded to the questionnaire were not born in Sweden, which might have helped to include the perspective of patients from other cultures.

Just 26 % of the patients in studies III and IV were women. However, this is consistent with the distribution of gender among the patients afflicted by an AMI according to register studies. These show that approximately 30-40% of the patient afflicted by an AMI, are women (8).

However, all included studies accounted for a reasonable grade of variance in delay. Furthermore the quantitative PLS-analyses of the influence of the subscales and items on patient delay was based on a broad set of data that deals with the content of the appraisal processes as related to patients' emotional and physical symptoms. The PLS regression respectively the PLS-DA implies several strengths i.e. the possibility to use wide data matrices i.e. a lot of variables in relation to the number of patients, and that co-linearity is no restriction. The robustness of the results was tested by conventional logistic regression analysis, yielding similar results.

CONCLUSION

Many patients with AMI still delay seeking medical care. This thesis adds knowledge on patients' behavioural response to their symptoms when afflicted by AMI. The pertinent shift in appraisal, the turning point, when patients change from self-regulative illness behaviour to care-seeking seems to be affected by partly contradictory influences. Emotional reactions such as *being incapacitated by fear, anguish and powerlessness, being ashamed of oneself, fear of losing a healthy identity and striving to avoid fear by not interacting with others* seem to be important and to have potential to influence patients' pre-hospital behaviour. The PA-AMI questionnaire showed satisfactory psychometric properties built on three core factors: *symptom appraisal, perceived inability to act* and *autonomy preservation*. The factors 'symptom appraisal' and 'perceived inability to act' had a major influence on patient delay.

The PA-AMI questionnaire can be used to assess the influence of the appraisal process on patient delay. In addition, it is important that this knowledge is used in the primary and secondary prevention in patients with risk for, or already manifest coronary heart disease.

An improvement in patients' behavioural response, i.e. a reduced patient delay when afflicted by an AMI should have great potentials to minimise morbidity and mortality.

CLINICAL IMPLICATIONS AND FUTURE RESEARCH

Clinical implications

- PA-AMI can contribute to the understanding of the care-seeking process in AMI as regards the entities *symptom appraisal* and *perceived inability to act*
- Education of patients about appraisal of symptoms and behavioural tendencies in the situation when afflicted by an AMI could be given in primary and secondary prevention
- In the education of health care personnel it is of importance to address the patients' appraisal, emotions and action tendencies prior to care-seeking when afflicted by an AMI
- It is possible that equivalents of PA-AMI could be used in patients with other diseases e.g. acute stroke

Future research

- Further studies is needed to fully understand the impact of *symptom appraisal* and *perceived inability to act* in the care-seeking process in patients afflicted by an AMI
- Emotional reactions such as fear, anxiousness, powerlessness and shame in relation to care seeking should be investigated more thoroughly in future studies

SVENSK SAMMANFATTNING

Introduktion

Akut hjärtinfarkt (AMI) är den vanligaste dödsorsaken i världen. Var sjätte man och var sjunde kvinna förväntas avlida i akut hjärtinfarkt. Huvudsyftet med tidig vård av patienter med hjärtinfarkt är att kunna behandla eventuellt hjärtstopp och minska skador på hjärtmuskeln och därmed minska sjuklighet och dödlighet. I Sverige har under de senaste årtiondena tiden från första symptom till medicinsk behandling minskat och är nu 170 minuter. Det innebär att nästan hälften av patienterna har en tidsfördröjning på över tre timmar innan de söker medicinsk vård. Forskning visar att patienternas tolkning av symtomens allvarlighetsgrad kan ha avgörande betydelse för beslutet att söka vård. Likväl kan känslor och hur patienterna agerar baserat på sina upplevelser av symptomen ha betydelse för beslutet.

Det övergripande syftet med denna avhandling var att öka kunskapen om patienters bedömningar och beteenden som kan påverka beslutet att söka medicinsk vård vid insjuknande i akut hjärtinfarkt.

Avhandlingen omfattar fyra delstudier, varav två (**I, II**) har en kvalitativ ansats och två (**III, IV**) har en kvantitativ ansats.

Studie I är en kvalitativ studie där fokusgrupper användes som datainsamlingsmetod. Syftet var att beskriva patienternas process från att de kände det första symtomet till beslutet att söka vård vid insjuknande i akut hjärtinfarkt. Fem gruppdiskussioner genomfördes och totalt deltog 15 patienter. Data analyserades utifrån den teoretiska modellen: 'Self-Regulatory Model of illness behaviour' (SRM). SRM-modellen utgår ifrån att patientens egna uppfattningar och föreställningar om ohälsa inverkar på hur de hanterar stressfyllda och känslomässigt krävande situationer som till exempel att insjukna i hjärtinfarkt. Modellen beskrivs som självreglerande och att processen med uppfattningar, föreställningar och känslor, hantering och bedömning fortsätter cykliskt tills patienten återfått hälsa.

Resultatet visade att det var svårt för patienterna att exakt ange tidpunkten för när de upplevde sina första symtom. Besvärens läge, intensitet och varaktighet varierade över tid och mellan olika patienter. Patienterna upplevde ångest och rädsla när besvären inte avtog. För att lindra besvären använde patienterna olika strategier till exempel att lägga sig ner, ta en promenad eller att använda smärtlindrande läkemedel. De sökte råd från till exempel husläkaren, vårdcentralen, vårdguiden, apotek samt akutmottagning. Det förekom också att

de undervärderade sina besvär och bedömde att de inte var så allvarliga. Vändpunkten då patienten beslöt att söka vård – ”the turning point” – baserades på svårtolkade känslor och en oförmåga att förstå eller kunna hantera situationen som en helhet om till exempel besvären inte gick över. Beslutet kunde vara patientens eget eller så överlät de beslutet till någon annan. För vissa patienter tog det lång tid från de första symtomen till ett beslut att söka medicinsk vård.

Studie II är en kvalitativ studie där individuella intervjuer användes som datainsamlingsmetod. Syftet var att öka förståelsen för de tankar, känslor och handlingar som föregick beslutet att söka medicinsk vård. Totalt intervjuades 14 patienter. Intervjutexten analyserades med innehållsanalys.

Resultatet kunde formuleras i fyra teman: handlingsförlamad av rädsla ångest och vanmakt; skämmas över sig själv; rädsla att förlora sin identitet som frisk; undvika kontakt med andra. Exempelvis var patienter oroliga för att de drabbats av en allvarlig sjukdom och de upplevde stark ångest när besvären inte avtog. De kände förtvivlan och maktlöshet när de inte fick kontakt med primärvården eller när de inte visste hur de skulle komma i kontakt med hälso- och sjukvården, men också en osäkerhet om hur sjuka de borde vara för att söka vård eller ringa efter ambulans. De uttryckte också att de var för stolta för att söka vård men tvingade sig till det. Det var svårt att ringa efter ambulans då de kände sig utsatta och generade om någon granne skulle se dem i den utsatta situationen. Det framkom också att de inte trodde att deras besvär kunde var en hjärtinfarkt eftersom de var relativt unga och de bortförklarade symptomen som ofarliga. Patienterna behöll sina besvär för sig själva då de inte ville oroa familj eller vänner då dessa hade tillräckligt med bekymmer i sina egna vardagsliv. De kände också tveksamhet till att följa hälso- och sjukvårdspersonalens råd att söka vård då de inte kände till eller var vana vid akutvården.

Studie III är en metodstudie där syftet var att utveckla och kvalitetsgranska ett frågeformulär för att kunna studera bedömningar, känslor och handlingar hos patienter som insjuknat i hjärtinfarkt. Frågeformuläret utvecklades av forskargruppen och baserades på resultaten i studie II. Ett antal påståenden togs fram som belyste tankar, känslor och handlingar som föregick beslutet att söka vård vid insjuknandet i akut hjärtinfarkt, samt generella påståenden om hur patienter agerar i allmänhet. I utvecklingen av frågeformuläret intervjuades 9 patienter och påståendena justerades på basis av intervjuerna. Statistiska analyser användes för att undersöka huruvida frågeformuläret mätte det som avsågs att mäta samt om frågeformuläret mätte de olika begreppen på ett tillförlitligt sätt. Totalt inkluderades 124 patienter.

Resultatet visade att frågeformuläret var tillförlitligt och att patienternas bedömningsprocess kunde formuleras i tre teoretiskt underbyggda faktorer: 'bedömning av symtom' 'uppfattad oförmåga att handla' samt 'vilja att bevara autonomi'.

Studie IV är en kvantitativ studie där frågeformuläret från studie III användes som datainsamlingsmetod. Totalt inkluderades 326 patienter. Syftet var att undersöka om och hur patienternas bedömning av sina symtom inverkar på tidsfördröjningen från första symtom till beslutet att söka vård samt om det var möjligt att särskilja patienter med kort respektive lång tidsfördröjning innan beslutet att söka vård vid insjuknande i akut hjärtinfarkt.

Resultatet visade att faktorerna 'bedömning av symtom' samt 'uppfattad oförmåga att handla' hade en inverkan på patienternas tidsfördröjning innan de tog beslutet att söka vård. Vid en jämförelse mellan patienter med kort tidsfördröjning (mindre än en timme) och övriga patienter hade 'bedömning av symtom' störst inflytande, medan 'uppfattad oförmåga att handla' hade störst betydelse vid en jämförelse mellan patienter med lång tidsfördröjning (mer än 12 timmar) och övriga patienter. Faktorn 'vilja att bevara autonomi' visade endast en inverkan i analysen vid jämförelse mellan patienter med en extrem lång respektive extremt kort tidsfördröjning.

Diskussion och slutsatser

- Många patienter som insjuknar i akut hjärtinfarkt väntar oönskat länge med att söka vård och detta verkar vara svårt att förändra.
- Tiden fram till en vändpunkt 'turning point', då patienterna ändrar sitt självreglerande beteende och istället beslutar sig för att söka vård verkar påverkas av flera ibland motsägelsefulla omständigheter och det kan ta en betydande tid för patienterna att komma fram till detta beslut.
- Denna avhandling bidrar till att belysa hur patienter bedömer sina kroppsliga och känslomässiga symtom vid insjuknande i akut hjärtinfarkt, och hur denna bedömning påverkar deras beteende när de drabbas av akut hjärtinfarkt.
- Patienterna upplevde känslor såsom rädsla, ångest, vanmakt och skam vilket kan bidra till en tidsfördröjning att söka vård.
- En ökad kunskap om patienternas bedömningsprocess kan ge nya möjligheter att förkorta tidsfördröjningen innan vårdsökande. Det utvecklade frågeformuläret skulle kunna användas för att få sådan kunskap.

- Att använda denna kunskap i utformandet av förebyggande undervisning till patienter som har risk för, eller som redan utvecklat kranskärlssjukdom, kan bidra till att minska patienternas tidsfördröjning vid ett eventuellt framtida insjuknande i hjärtinfarkt. En förkortning av tiden från första symtom till beslut att söka vård kan i sin tur bidra till att minska sjuklighet och död i akut hjärtinfarkt.

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