

Illness Perception and Fatigue after Myocardial Infarction

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ABSTRACT

Treatment of myocardial infarction (MI) has undergone major advances in recent years, including reductions in mortality and hospital stays. To optimize patients' recovery, secondary preventive strategies are important. However, many patients fail to attend to such programmes as well as recovery. Other obstacles are post-MI fatigue and depression. The main focus of the present thesis was to explore illness perception and fatigue after MI. A secondary aim was to investigate the levels of illness perceptions and fatigue and their relationships with demographic/clinical variables, depression, anxiety and health-related quality of life (HRQoL). In Study I, patients' illness perception of MI was explored. The methodology used was grounded theory (25 informants interviewed). The core categories *illness reasoning* and *trust in oneself* vs. *trust in others* were found to be fundamental in viewing the MI either as an acute isolated heart attack or as a sign of a chronic condition. In Study II, the aim was to gain a deeper understanding of what fatigue means to patients with recent MI and how they managed to deal with the consequences of fatigue. Grounded theory was applied also in this study (19 informants interviewed). A central theme was labelled *living with incomprehensible fatigue*. This core category was featured by several properties: *different kind of tiredness, unrelated to effort, unpredictable occurrence, and unknown cause*. In Study III, the incidence of fatigue in 204 consecutive MI patients was examined and compared to reference populations. Gender differences in fatigue were also examined, as well as changes over time and the relationships between fatigue versus clinical and demographic variables and measures of emotional distress. The Hospital Anxiety and Depression Scale (HADS) and the Multidimensional Fatigue Inventory (MFI-20) were used. MI patients reported higher levels of fatigue compared with the general population, depression and fatigue overlapped, but 33% reported fatigue without coexisting depression. No gender differences were found. In Study IV, illness perceptions in 204 consecutive MI patients were examined using the Illness Perception Questionnaire (IPQ-R) and compared to reference populations. Changes in illness perceptions over time were also examined, as well as the relationships between illness perceptions and anxiety/depression (HADS), fatigue (MFI-20), somatic health problems (SHCQ) and HRQoL (SF-36). It was shown that illness perceptions changed over time, from viewing the MI as an acute event to a more chronic condition, and that the beliefs in personal and treatment control of MI decreased. These negative beliefs were associated with fatigue and lowered HRQoL. In conclusion, the studies contribute to our understanding of how patients perceive their MI, and particularly that fatigue is a notable symptom affecting patients' lives. Individualized secondary preventive strategies could start with identifying patient's unique illness perception. It is also important to identify patients who are fatigued to provide adequate treatment as well as to prevent progression from fatigue to exhaustion.

Keywords: anxiety, depression, fatigue, health-related quality of life, illness perception, myocardial infarction

ORIGINAL PAPERS

The thesis is based on the following papers, referenced in the text by their Roman numerals I-IV

- I. Alsén, P., Brink, E. & Persson, L-O. (2008). Patients' illness perception four months after a myocardial infarction. *Journal of Clinical Nursing*, 17(5A), 25-33.
- II. Alsén, P., Brink E. & Persson, L-O. (2008). Living with incomprehensible fatigue after recent myocardial infarction. *Journal of Advanced Nursing*, 64(5), 459-68.
- III. Alsén, P., Brink, E., Brändström, Y., Karlsson, B. & Persson, L-O. Fatigue after myocardial infarction: Relationships with indices of emotional distress, and sociodemographic and clinical variables. *(Submitted for publication)*
- IV. Alsén, P., Brink, E., Brändström, Y., Karlsson, B. & Persson, L-O. Illness perceptions after myocardial infarction; relations to fatigue, emotional distress, and health-related quality of life. *(Submitted for publication)*

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ABBREVIATIONS

ACE	Angiotensin-Converting Enzyme
CABG	Coronary Artery Bypass Grafting
CRP	C-reactive protein
CSM	Common Sense Model of Self-Regulation
CVD	Cardiovascular Disease
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders
ECG	Electrocardiogram
EF	Ejection Fraction
GAS	General Adaptation Syndrome
GT	Grounded Theory
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health-Related Quality of Life
IPQ-R	Illness Perception Questionnaire–Revised
MDD	Major Depressive Disorder
MFI-20	Multidimensional Fatigue Inventory
MI	Myocardial Infarction
PCI	Percutaneous Coronary Intervention
QOL	Quality of Life
SF-36	Short Form-36
SHCQ	Somatic Health Complaint Questionnaire
SPSS	Statistic Package for the Social Sciences
Tnt	Troponin-T
WHO	World Health Organization

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INTRODUCTION

Surviving a Myocardial Infarction (MI) is often the beginning of a long period of rehabilitation. Although improved acute treatment in the coronary care unit, optimised follow up treatment including risk factor handling and cardiac rehabilitation programmes help people recover (Jolliffe et al. 2001; Stagmo et al. 2004), many patients still suffer from various prolonged symptoms such as fatigue, emotional distress and chest pain (Lee et al. 2000; Gravely-Witte et al. 2007; Fridlund 2000).

Cardiac rehabilitation and lifestyle modifications are essential components of successful recovery after MI. However, many patients fail to attend rehabilitation programmes or to modify their lifestyle (Cooper et al. 2002). It is therefore important to further explore possible factors that may hinder patients with MI from taking appropriate health-promoting actions. Earlier research has shown that the patients' own perceptions about health and illness may influence their attendance to rehabilitation programmes as well as their recovery (Whitmarsh et al. 2003; Petrie et al. 1996; French et al. 2006). Other important factors that may serve as hindrances are depression (Ladwig et al. 1994; Dobbels et al. 2002) and fatigue (Crane 2005). The main focus of the present thesis is on exploring patients' illness perception, perceived fatigue and emotional distress (depression and anxiety) after being stricken by an MI.

Cardiovascular diseases (CVD) are the leading cause of mortality in both men and woman worldwide (Gaziano 2008). According to statistics from the National Board of Health and Welfare in Sweden (2008), acute MI accounts for 16% of deaths in men and 11% in women. Both the incidence of acute MI and the mortality are related to sex and age. In 2006, the incidence for men was 667 per 100,000 and for women 477 per 100,000. For the women in a given age group, the incidence is the same as for men who are five to ten years younger. However, mortality decreased during 2006 among males, but remained at the same level among women. In total, about 15% of people with acute MI die within 28 days (NBHW 2008a).

Risk factors that account for MI worldwide are abnormal lipids, smoking, history of hypertension, diabetes, abdominal obesity, psychosocial factors (depression, locus of control, perceived stress and life events), low intake of fruits and vegetables, high alcohol consumption, and lack of regular physical activity (Yusuf et al. 2004).

The primary underlying cause of MI is atherosclerosis, an inflammatory disease in the arteries which thicken the innermost layer of the artery, the intima (Hansson et al. 2006). A coronary event results from an unstable and ruptured atherosclerotic plaque, which generates an obstruction of the coronary artery and consequently decreases the blood flow (Libby & Sasiela 2006). The definition of MI reflects myocardial cell death caused by prolonged ischemia. In clinical settings, MI is diagnosed when a cardiac biomarker is elevated together with evidence of myocardial ischemia, including at least one of the following criteria: symptoms, changes of electrocardiogram (ECG) or imaging evidence of new loss of viable myocardium (Alpert et al. 2008).

The predominant symptom of acute MI is chest pain (Goldberg et al. 1998; Omran & Al-Hassan 2006; DeVon et al. 2008), although it has been suggested that 21% of women and 10% of men experience no chest pain at all (DeVon et al. 2008). However, gender differences seem to exist in perceived symptoms, i.e. women are less likely to report symptoms of chest pain. Further, compared to men, women are more likely to report shortness of breath, nausea, vomiting, back pain, jaw pain, neck pain, cough and fatigue (Chen et al. 2005).

Treatment of acute MI has undergone major advances during recent decades, leading to reductions in short- and long-term mortality and shortened hospital stays (Stenestrand et al. 2006). This depends in part on the early use of thrombolysis, Percutaneous Coronary Intervention (PCI) or Coronary Artery Bypass Grafting (CABG), resulting in rapid reestablishment of coronary flow (Stenestrand et al. 2006; Van de Werf et al. 2003; Faxon 2005). Also, pharmacological treatments, for example the use of antiplatelets, Beta-blockers and Angiotensin-Converting Enzyme (ACE) inhibitors are associated with lower short- and long-term mortality in patients with MI (Stenestrand et al. 2005).

The recovery process after an MI is a vulnerable period both physically and emotionally (Daly et al. 2000; Kristofferzon 2006). Patients have to deal with physical symptoms and emotional distress (Johansson et al. 2003; Furze et al. 2005; Lau-Walker 2007); they sometimes also have to deal with fatigue and symptoms of depression and/or anxiety (Pedersen et al. 2007; Mallik et al. 2005; Bush et al. 2005).

Secondary prevention is of great importance to improving health outcomes (Clark et al. 2005). It includes all actions taken to reduce the risk of future death, re-infarction, and progression of the illness (NBHW 2008b; De Backer et al. 2003). After the acute phase of MI, Swedish patients are usually directed to cardiac rehabilitation programmes. According to the World Health Organization (WHO), rehabilitation is considered to be an essential part of care for individuals recovering from MI. The goals are: "To improve functional capacity, alleviate or lessen activity-related symptoms, reduce unwarranted invalidism, and enable the cardiac patient to return to a useful and personally satisfying role in society" (WHO 1993 p. 1). Cardiac rehabilitation refers to interventions designed to optimize patients physical, psychological, and social functioning, in addition to stabilizing, slowing, or reversing progression of the underlying atherosclerotic processes, and thereby reducing morbidity and recurrent heart disease (Leon et al. 2005). Guidelines have been developed with recommendations for coronary heart disease patients, which include the role of lifestyle changes and management of cardiovascular risk factors (NBHW 2008b; De Backer et al. 2003). Therefore, an important task for research on recovery from MI is to understand factors that influence an individual's adherence to secondary preventive strategies and health behaviour.

BACKGROUND

Illness and disease

There is a distinction between “disease” and “illness”, where disease is defined as “abnormalities in the structure and the function of the body and organ systems” and illness as “experiences of disvalued change in states of being and in social functioning” (Eisenberg 1977 p. 11). A disease can be acute or chronic. An acute disease develops with a sudden onset, with signs and symptoms related to the disease process itself, and end after a relatively short time, with recovery and continuations of prior activities, or with death. A chronic disease can appear suddenly or through an insidious process, it can be episodic, or remain in remission with absence of symptoms for long periods of time (Larsen 2006).

Illness refers to individuals’ lived experience of monitoring bodily processes, involving appraisal of those processes as expectable, serious, or requiring treatment. Illness also includes categorizing and explaining the distress caused by the pathological processes as well as how to cope with the distress and the practical problems it creates. Illness problems are the difficulties created by symptoms and disability. Illness experiences are culturally shaped by the way we have learned to think and act and by how we understand and treat an illness (Kleinman 1988).

Illness Perception

Perception is described as the process by which the individual interprets and organizes sensations and events to produce a meaningful experience of the world (Lindsay & Norman 1977). These interpretations are guided by the specific knowledge, beliefs and expectations characterizing the individual. Perception also refers to how people understand and make sense of diseases and/or disabilities, e.g. illness perceptions. In this respect, illness perceptions to some extent correspond to the conceptualizations of illness in contrast to disease. Research has shown that people vary in how they perceive their health status and that these perceptions often are independent of the actual physical condition (Taylor et al. 2000). For example, people vary in how they perceive their possibilities to influence or control their health (Wallston 2004), whether their condition is acute or chronic (Lau & Hartman 1983) or whether or not their specific situation is hopeful (Scheier & Carver 1985). Such perceptions may in turn determine individuals’ behaviour as well as their response to managing health threats related to a disease or a symptom.

The common sense model of self-regulation

The most elaborated theory of how people perceive their illness situation has been developed by Howard Leventhal and is called the *Common Sense Model of Self-Regulation* (CSM) (Leventhal et al. 1980; Leventhal et al. 1984; Leventhal et al. 1997; Leventhal et al. 2001). The basic premise of CSM is that individuals are active problem-solvers who make sense of a threat to their health (Leventhal et al. 1984). Individuals are motivated to regulate or minimize their health-related risk and to decrease health threats in ways consistent with their own perceptions. If healthiness is the in-

dividual's normal state, illness will be interpreted as a problem to be solved by the individual (Leventhal et al. 2003). Illness episodes are affected in parallel by contextual factors such as biological characteristics, psychological traits, coping preferences (actual and perceived self), as well as the individual's perceived role in a social and cultural context (Leventhal et al. 2001).

CSM refers to three broad stages: First, an internal or an external stimulus is interpreted by the individual, who forms a picture of the illness threat. The cognitive factors and the emotional reaction to the stimulus form *illness representations*. These are primary guides to the second stage, which includes action plans for *coping strategies* to deal with the problem and the emotion. Coping also involves the development of action plans to manage and cope with the illness. The third stage involves *appraisal* in which the individual uses specific criteria for successful coping actions based on how the problem is defined or represented, their own abilities to perform the action and their impact on desirable outcomes (Leventhal et al. 1984; Leventhal et al. 2003).

According to the model, illness perceptions in the representation stage of the model are clustered around five dimensions of health threats: (1) *identity* of threat, the symptoms that patients attribute to the illness, (2) the *time line* dimension is a measure of the perceived duration of the illness, (3) the *consequences* of the illness, which measure the perceived impact the illness has on the patient's life, (4) beliefs about its *cause*, and (5) beliefs about the *controllability* of the illness (Leventhal et al. 2003). Each dimension is related to individuals' beliefs about factors related to their symptom or illness. These make up the patient's overall *perception* of the illness. It should be noted, however, that in the health context, the terms belief and perception are often used synonymously.

Symptoms

Symptoms are explained as "the expressions of experience of distress, communicated as an ordered set of complaints" (Good 1994 p. 8), as well as expressions of the sufferer's reality, which constitutes the personal meaning of illness (Good & Good 1981). A symptom refers to a subjective experience of illness reflecting changes in the bio-psychosocial functioning, sensations, or cognition of an individual. In contrast to a symptom, a sign refers to an objective indication of disease (Harver & Mahler 1990).

Symptom experience is an interaction between perception, evaluation and the meaning of and response to a symptom. Symptom perception refers to whether the individual notices a change from the way he or she usually feels or behaves, and evaluation refers to the individual's judgements about the severity, cause, treatability of the illness and the effects symptoms have on his or her life. Finally, symptom response includes physiological, psychological, socio-cultural and behavioural components (Dodd et al. 2001a). Symptoms also constitute communication structures, in that they express health disorders, the problems and pleasures of everyday life, as well as the sorrows that would otherwise find no expression (Honkasalo 1989). Further, patients of different ethnic and cultural backgrounds vary in their expression of and concerns about the meaning of symptoms, but also in the nature of their response to therapeutic strategies (Good & Good 1981).

Some symptoms, especially complaints such as fatigue and pain, have no definite medical diagnosis or explanations as to a clear cause. This is due to a lack of measurable correlates and to possible changes in symptom quality and intensity over time (Kirmayer et al. 2004). Symptoms can occur alone or in isolation from one another, but more often multiple symptoms are experienced simultaneously. If two or more symptoms occur at the same time, they are likely to affect each other, e.g. pain is worse when fatigue or nausea occurs at the same time, and the intensity of a symptom, such as pain, may mask another symptom, such as fatigue. When three or more symptoms occur together and are related to each other, they are defined as forming a symptom cluster (Dodd et al. 2001b).

Fatigue

Fatigue is a universal symptom associated with acute and chronic illness, but also with healthy functioning and everyday life (Aaronson et al. 1999). It is a common and complex symptom with wide-ranging implications for the fatigued patients lives (Ream & Richardson 1996) and is reported to be distributed continuously in the general population (Loge et al. 1998). Fatigue is associated with diseases such as MI (Brink et al. 2005; Appels et al. 1995; Pedersen & Middel 2001), chronic heart failure (Ekman & Ehrenberg 2002; Falk et al. 2007), multiple sclerosis (Flensner et al. 2003), chronic fatigue syndrome (Larun & Malterud 2007), and depression (Pedersen et al. 2007, Lee et al. 2000). It is also a common side effect of various cancer treatments (Smets et al. 1998; Stone et al. 2001; Ahlberg et al. 2005; Browall et al. 2008). Moreover, fatigue is associated with measurements of impaired Quality of Life (QOL) (Janardhan & Bakshi 2002).

A wide range of definitions of fatigue are found in the literature. One concept, often used synonymously with fatigue, is *vital exhaustion*, which is characterized by unusual fatigue and lack of energy, increased irritability and feelings of demoralization (Meester & Appels 1995). Grandjean (1970) described fatigue as a continuum ranging from tiredness, at one end, to exhaustion, at the other. Similarly Ream and Richardson (1996 p. 527) defined fatigue as “a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals’ ability to function to their normal capacity”. Others have described fatigue as a multidimensional construct with components of general fatigue, physical fatigue, and reduction in activity, motivation and mental activity (Piper 1993; Smets et al. 1995).

The subjective nature of fatigue is included in the Nursing Diagnosis definition as: “the self-recognized state in which a person experiences an overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work that is not relieved by rest” (Carpenito-Moyet 2008 p. 245). Fatigue is also conceptualized as an imbalance between the individual’s awareness of insufficient capacity for physical and/or mental activity, either because the demand or need is too great or because the utilization and restoration mechanisms are disturbed (Aaronson et al. 1999).

In the nursing literature, the terms tiredness and weakness are most frequently used synonymously with fatigue. However, tiredness is a universal sensation that is experi-

enced by everyone, expected to occur normally at certain times of the day, and should not be interpreted as always preceding fatigue or exhaustion on a continuum (Ream & Richardson 1996). In contrast to tiredness, subjective fatigue is abnormal, unusual and unrelated to activity or rest (Piper 1993; Carpenito-Moyet 2008). Fatigue affects both physical and mental abilities and has vast consequences for the individual's functioning (Hart et al. 1990), including irritability, impaired thought processes, inability to make decisions, inability to concentrate, inability to cope, forgetfulness and poorer motivation (Hubsy & Sears 1992).

An elaboration of the relations between tiredness, fatigue and exhaustion resulted in a Fatigue Adaptation Model (Olson 2007a; 2007 b). This model suggests that fatigue is not a continuum, but rather a *state* along a continuum with tiredness and exhaustion as distinct states located at the ends of an adaptation continuum. This is in a sense consistent with the stress theory described by Selye (1952). He described stress as a non-specific response to any demand, whether pleasant or unpleasant. He argued that stress triggers general adaptation syndrome (GAS), a psychological response that comprises an alarm reaction, resistance and exhaustion. Tiredness is an adaptive response to stressors that occur during the alarm phase of GAS. If adaptation is not effective, individuals eventually progress to fatigue. Fatigue indicates a declining ability to adapt to stressors that occur during the resistance phase of GAS. An individual can move back to tiredness if the adaptive response is effective. If adaptation is not effective, the outcome may be progression to exhaustion. Exhaustion indicates an inability to respond to stressors occurring during the exhaustion phase of GAS (Olson 2007).

Depression and anxiety

Depression is one of the major public health concerns (WHO 2001), with a lifetime risk of 20% for men and 30-35% for women (Mattisson et al. 2005). The criterion for diagnosis of a Major Depressive Episode according to DSM-IV (American Psychiatric Association 2000) requires the presence of at least one of two “core” symptoms, depressed mood and loss of interest in pleasure, together with at least three associated symptoms: change in weight or appetite, sleep disturbance, psychomotor agitation or retardation, fatigue, feeling worthless or guilt, problems with concentration, and thoughts of death.

Depression often occurs together with anxiety, which in turn could be described as an intense unpleasant emotional state characterized by feelings of worry and by activation of arousal of the autonomic nervous system. According to DSM-IV, anxiety or worry is associated with three or more of the following symptoms: restlessness, being easily fatigued, difficulty in concentrating, irritability, muscle tension and sleep disturbance (American Psychiatric Association 2000). Just as for depression, the prevalence of anxiety is more common among women (30%) than among men (20%) (Sadock et al. 2007).

Health-related quality of life

Health-Related Quality of Life (HRQoL) is a multidimensional concept referring to how people perceive aspects of their lives that relate to their health (Fuhrer 2000).

This is in contrast to quality of life, which is broader and relates to individuals' perceptions of their position in all areas of life. In this respect, HRQoL rests on both the concept of health and the concept of quality of life (WHOQOL 1998). Thus far, there is no single and accepted definition of HRQoL, but there is a consensus that assessments should include perceptions of general health, physical functioning, physical symptoms, emotional functioning, cognitive functioning, role functioning, social well-being and functioning, sexual functioning and existential issues (Sullivan et al. 2002; Fayers & Machin 2007).

STATE OF KNOWLEDGE

Illness perception and myocardial infarction

Individuals who have positive illness perceptions identify the signs and symptoms and the cause of the disease, view their illness as controllable or curable, and feel that the course of the disease is intermittent and that the level of consequences is low. It has been reported that after an MI patients with negative perceptions of their illness experienced more complications (Cherrington et al. 2004). It has also been shown that MI patients who perceive their condition as serious and having long-lasting consequences have more illness-related disability, are slower to return to work, and have more disability in recreational activities and social interactions (Petrie et al. 1996). Individuals with stronger beliefs that the condition is controllable, and who also attributed their heart condition to their lifestyle, showed higher cardiac rehabilitation attendance (Cooper et al. 1999). An intervention study by Petrie et al. (2002), which aimed at altering patients' illness perception concerning their MI, revealed significant positive changes. Patients in the intervention group were better prepared for leaving hospital, and returned faster to work than did patients in the control group. A lower rate of angina was also shown in the intervention group, but there were no differences between the two groups in attendance at cardiac rehabilitation. Further, there is a relationship between self-efficacy and illness perception, such that the greater the perceived consequences, the lower the self-efficacy to cope with the heart condition situation. Moreover, the longer the perceived duration of the condition, the higher the specific self-efficacy to change and maintain a diet or exercise regimen (Lau-Walker 2004).

There is also a distinction concerning the extent to which the MI is understood as an acute event rather than a sign of a chronic condition. Beliefs about the heart attack as an acute event rather than a symptom of a chronic condition seem to result in low motivation for lifestyle changes (Wiles & Kinmonth 2001). These dimensions were also associated with experiences of the heart attack as mild or severe. Individuals who had suffered a mild heart attack, and/or those who did not identify themselves as coronary heart disease patients, viewed their MI as an acute event rather than a sign of a chronic condition (Brink et al. 2006). It has also been shown that patients' own ideas about the damage to their heart were only weakly related to actual damage (troponin-T). Subjective beliefs influenced the recovery phase more than medical indicators of damage did. Patients who perceived that their heart had been badly damaged by their MI reported lower perceived control and longer perceived duration of their condition. Also, return to work was associated with perceptions about the magnitude of damage to the heart (Broadbent et al. 2004).

Fatigue and myocardial infarction

Fatigue is a common symptom in patients with cardiovascular disease, which at extreme levels may develop into a state of vital exhaustion (Appels et al. 2005). Many patients also feel exhausted after an MI (Schuitemaker et al. 2004). Five months after a first-time heart attack, fatigue was patients' most bothersome symptom. It kept

them from taking part in activities they participated in prior to the infarction (Brink et al. 2006). Time, however, did not produce uniform improvements in fatigue. For some individuals, fatigue actually increased as time passed and for others the level was high from the beginning and did not improve (Lee et al. 2000). Fatigue has also been reported to be a problem in recovery after MI. Six weeks post-MI, fatigue was experienced by women as chronic, generalized, intermittent and longstanding. More than one-third of the subjects also attributed their fatigue directly to their heart attack or hospitalization. Those with higher fatigue scores reported lower psychological well-being and lower adaptive health behaviour (Varvaro et al. 1996). Crane (2005) reported that, 6-12 months after MI, fatigue was a frequent symptom in older woman who also perceived this fatigue to be different from that experienced before MI. The use of Beta-blockers reduces mortality after MI (Houghton 2000). However, it has also been suggested that Beta-blocker therapy might constitute a further reason for increased fatigue among patients with MI (Ko et al. 2002).

Depression and myocardial infarction

Major Depressive Disorder (MDD) is the most commonly observed psychiatric condition in cardiovascular disease (Schleifer et al. 1989; Ziegelstein 2001; Thombs et al. 2008) and is associated with an increased risk of morbidity and mortality (Fraisure-Smith et al. 1995; Lett et al. 2004; Bush et al. 2001; Frasure-Smith & Lesperance 2003). Symptoms of depression and fatigue tend to overlap in patients with MI (Irvine et al. 1999), as one of the cardinal symptoms of depression is fatigue or loss of energy (American Psychiatric Association 2000). However, symptoms of fatigue can also occur without coexisting depression (McGowan et al. 2004). Brink and Grankvist (2006) explored the relationship between pessimism/optimism, fatigue and depression and concluded that manifestation of fatigue may be influenced by a pessimistic view leading to more negative consequences, this compared with an optimistic view of life leading to positive consequences.

Health-related quality of life and myocardial infarction

It has been shown that after an MI, survivors have reduced HRQoL in most health domains compared to their peers (Plevier et al. 2001). In a Swedish study, MI patients examined five months after an acute MI had considerably lower scores in both physical and mental domains of HRQoL compared with the general population (Brink et al. 2002). The same study showed that women reported poorer physical health than men did. In a follow-up study after one year (Brink et al. 2005), HRQoL had improved, but mental health was still below the norms. Brown et al. (1999) have even reported that both men and women under 65 years had lower scores on HRQoL (SF-36) up to four years after an acute MI, as compared with normative scores for the community.

RATIONALE

The rationale for the present study is to explore factors that can influence (improve/hinder) individuals' adherence to secondary preventive strategies during recovery from MI.

Successful lifestyle changes and attendance to rehabilitation programmes are dependent on how patients' perceive their illness and their illness situation (illness perceptions), as well as on fatigue, emotional distress and HRQoL. There has also been little research on the relationships between these factors and how they may change over time.

AIMS OF THE THESIS

The overall aim of the present thesis was, first, to explore from the patients' perspective illness perception and experiences, and the prevalence and consequences of fatigue and, second, to examine the levels of and relations between illness perception and fatigue, clinical and demographic variables, depression, anxiety and HRQoL.

The specific aims were to;

- I Obtain an increased and deeper understanding of post-myocardial patients' illness perception.
- II Gain a deeper understanding of what fatigue means to patients with recent MI and how they manage to deal with the consequences of this symptom.
- III Compare the incidence of fatigue among patients with MI with a general population and with other clinical populations, and to examine gender differences and changes in fatigue from the first week to four months after the MI. Further to find associations between fatigue, depression, and clinical and demographic data, and finally to examine the incidence of fatigue without coexisting post-MI depression.
- IV Examine illness perceptions among MI patients and compare them with selected reference populations, and to examine relations between illness perceptions and fatigue, HRQoL, emotional distress (anxiety, depression) and somatic symptoms. Further to examine changes from the first week to four months after the MI.

Perspective

The perspective taken here is a nursing science outlook, where the aim is to describe, explain and understand the nature of phenomena related to nursing care (Meleis 2007). The focus is on illness rather than disease, indicating that the patients' experiences are central to a nursing perspective. The most imported data are self-reported, both from a qualitative explorative perspective and from a quantitative comparative perspective. The use of a multi-method research design (Morse 2002) may enhance our understanding of the complex phenomena of illness perception and fatigue after MI.

METHODS

Designs

The studies that make up the present thesis are part of a longitudinal research project focused on patients' life consequences after MI. In order to gain knowledge about patients' illness perception and fatigue after an MI, both inductive and deductive research methods were used, i.e. qualitative analyses in Study I and II and quantitative analyses in Study III and IV (Table 1). When the purpose was to examine patients' subjective meaning and experience of illness perception and fatigue, qualitative methods were chosen. When the purpose was to examine levels of illness perception and degree of inconvenience caused by fatigue in various stages, a longitudinal, quantitative design was applied. Correlations between different variables and comparisons between different groups were conducted using this design. Combining these approaches allows the patient perspective to be the central focus, which facilitates a broader understanding of patients' perception and fatigue after MI.

Table 1. An overview of variables, instruments and methods

Study	I	II	III	IV
Design	Explorative Comparative Descriptive	Explorative Comparative Descriptive	Longitudinal descriptive correlation comparative	Longitudinal descriptive Correlation comparative
Demographics	Age Gender	Age Gender	Age Gender Educational level Cohabiting	Age Gender Educational level Cohabiting
Clinical variables			Beta-blocker Presence of Q-wave Ejection fraction Troponin-T CRP Interventions Comorbidity Days in hospital	Presence of Q-wave Ejection fraction Troponin -T CRP Interventions Comorbidity
Instruments	Interviews	Interviews	Questionnaires; MFI-20 HAD scale SHCQ	Questionnaires; IPQ-R MFI-20 HAD scale SHCQ SF-36
Subjects Analysis	25 Constant comparative analysis	19 Constant comparative analysis	204 Descriptive statistics, chi- square test, <i>t</i> -tests, Pearson correlations	204 Descriptive statistics, chi- square test, <i>t</i> -tests, Pearson correlations

Settings

The present studies were conducted at two coronary care units - Uddevalla Hospital and Norra Älvsborg County Hospital (NÄL) in Trollhättan, Sweden. These regional hospitals serve a population of 275,000. About 750 patients are treated here for acute MI every year. Data collection was performed during the period October 2005 to September 2006 and included consecutive patients (≤ 80 years of age) with a diagnosis of MI.

Sampling (I-IV)

All studies (I-IV) utilized empirical data from consecutive patients admitted to the hospitals with a diagnosis of MI. During their first days in hospital, patients were asked to participate in a longitudinal study on health and life consequences of MI. Of the 310 patients invited, 74 declined and 236 agreed to participate. Four months after the initial MI, 32 patients had declined further participation. Thus, a total of 204 patients filled in questionnaires one week after the MI and after four months (Figure 1). Of these patients, 26 participants were selected for Study I and II.

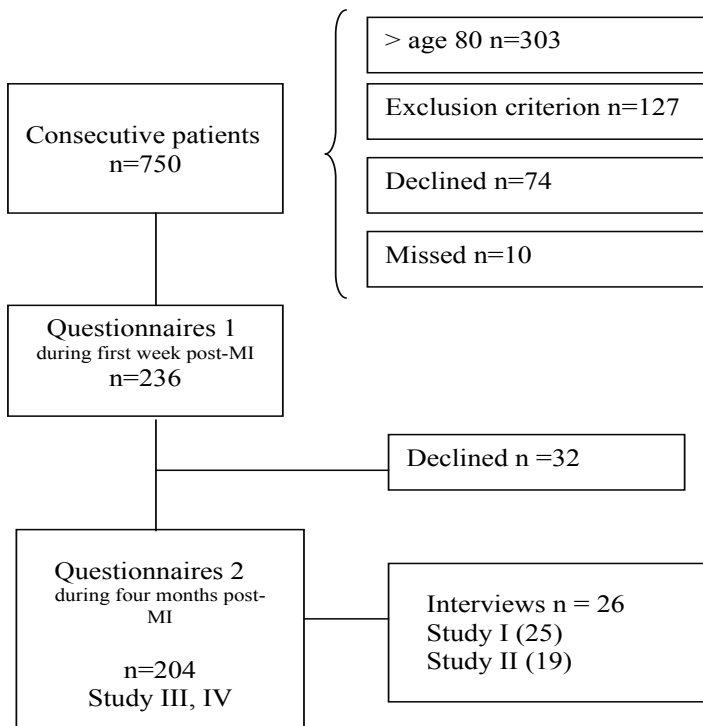


Figure 1. Patient flow and data availability for all studies.

Participants

Study I and II

In Study I, 25 informants (9 women) were interviewed about their illness perceptions concerning their recent MI four months after admission. The patients were chosen among those who had completed the questionnaires on both occasions (n=204). Of the 25 informants, 18 patients (7 women) and an additional woman (n=19) were also interviewed about what fatigue has meant to them and how they have managed to deal with the consequences of this symptom (Study II). For those included in Study II, an inclusion criterion of $\geq 15/20$ on any of the dimensions of the Multidimensional Fatigue Inventory (MFI-20) (*general fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue*), four months after MI was established. To achieve variation in the interview data, patients were also selected to form a heterogeneous group with respect to age, gender and main treatment. In Study I, according to the constant comparison methodology, data collection and analysis progressed simultaneously in that an additional 6 patients (with scores below 15 on MFI-20 /none fatigued) were selected for interviews about their illness perceptions. This was done to form a heterogeneous group and to add new data.

Study III and IV

During the first week after MI, 236 patients filled in questionnaires concerning demography, illness perceptions (IPQ-R), depression/anxiety (HADS), and fatigue (MFI-20). Four months after discharge from hospital, the patients were contacted to complete the questionnaires a second time. On this second assessment, questionnaires concerning physical symptoms (SHCQ) and health-related quality of life (SF-36) were added. In the follow-up contact, 32 patients declined participation. Thus, the full sample consisted of 204 patients in Study III and IV.

Inclusion and exclusion criteria

The inclusion criteria were a clinical diagnosis of MI, based on symptoms, electrocardiographics and enzymatic criteria. Informed consent was required. In Paper II, only respondents with a score of $\geq 15/20$ on any of the fatigue dimensions (MFI-20) were included. Excluded were subjects older than 80 years, and subjects with cognitive disorientation and communicative disabilities (e.g., dementia, stroke), other severe diseases, and/or an inability to understand and speak Swedish.

Data collection and procedure

Study I and II (interviews)

In order to gain a deeper understanding and provide a rich description of patients' illness perception after an MI (Study I) and also to explore and describe patients' experiences of perceived fatigue after an MI (Study II), constructivist Grounded Theory (GT) methodology, based on the work of Charmaz (2000; 2006), was chosen. Originally, GT was developed by Glaser and Strauss (1967), reformulated by Strauss and Corbin (1990) and later by Charmaz (2000). A GT method is one of the qualitative research approaches suited to the purpose of theory development or to elaborating and modify-

ing existing theory in light of new data (Strauss & Corbin 1998). GT was developed with the purpose of studying social phenomena (Glaser & Strauss 1967) and is based on the theoretical underpinnings of symbolic interactionism (Blumer 1969). This perspective leads one to look at the self and meanings as processes that are constructed through interactions with others (Charmaz 2000). GT, placed within a constructivist paradigm, assumes relativist ontology, implying that there are multiple social realities rather than one reality. It also views the nature of reality as a specific mental construction developed by an individual, implying that multiple mental constructions exist with respect to reality (relativism). Epistemologically, knowledge is created transactionally by the viewer and the viewed (Guba & Lincoln 1994).

Four months after discharge from hospital, patients were contacted and asked to participate in an interview. The time and place of the interview were agreed upon. Most of the interviews took place at the informant's home, with the exception of some interviews that were conducted in a private room at the hospital. Each interview lasted between 40 to 90 minutes. The interviews contained questions concerning informants' illness perception of their recent MI. To introduce the topic, an initial open-ended question was asked: "Tell me about what happened when you were stricken with the heart attack". Based on the response to this question, follow-up questions were asked: "Tell me what you think today about having a heart attack" and "what are you doing to improve your situation"? For patients included in Study II, questions were also asked about their fatigue experience: "How do you describe your experience of fatigue after an MI? What do you feel, think and do about it? What is the main concern caused by your fatigue and how are you trying to manage the situation?" Because there is no accepted word for fatigue in everyday spoken Swedish, the Swedish word used during the interviews was 'trött'. Each interview was tape-recorded and then transcribed verbatim.

Study III and IV (questionnaires)

The first questionnaire packet included baseline characteristics and demographics and was answered during the first week in hospital. Clinical and medical data (troponin - T, left ventricular ejection fraction, pharmacological treatment and co-morbidities) were collected from patients' medical records. The second questionnaires were sent by post to patients' homes after four months, along with a pre-stamped return envelope. One reminder was sent out.

Measurement and instrument (III, IV)

The Illness Perception Questionnaire - Revised (IPQ-R)

The Illness Perception Questionnaire (IPQ) (Weinman et al. 1996) was developed to provide a quantitative assessment of the five components of the illness perceptions (*identity, consequences, timeline, control/cure and cause*) in Leventhal's Common Sense Model of Self-Regulation (Leventhal et al. 1997). Later, Moss-Morris and colleagues (2002) modified the original version and added new subscales to create the Revised Illness Perception Questionnaire (IPQ-R), which comprises nine dimensions (*identity, cause, timeline acute/chronic and cyclical, consequences, personal control, treatment control, illness coherence and emotional representation*).

The IPQ-R was translated to Swedish after obtaining permission from the authors. The translation into Swedish was made by forward and backward translation, in a two-stage procedure (Fayers & Machin 2000). Two Swedish-speaking translators (registered nurses with knowledge in the field) performed the forward translation independently. Discrepancies between their versions were resolved. Thereafter, a backward translation into English was performed by an authorized, native English translator, and further discrepancies were resolved. Cronbach's alpha reliability coefficients were calculated for each of the dimensions assessed by IPQ-R. These ranged from 0.65 to 0.86 at the assessment one week after the MI, and from 0.70 to 0.86 at the assessment four months after the MI. Alphas of the original IPQ-R subscales ranged from 0.79 to 0.89 (Moss-Morris et al. 2002).

In the present study, the dimensions of *timeline (acute/chronic and cyclical)*, *consequences*, *personal control*, *treatment control*, *illness coherence* and *emotional representation* were used with measurement points during the first week and four months after MI. The scales are built up from 38 statements. Patients are asked to indicate their level of agreement on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree*. In the scales *timeline (acute /chronic, cyclic)*, higher scores indicate stronger beliefs that the condition is lasting and chronic and cyclical, rather than acute in nature. In the *consequences* scale, higher scores represent stronger beliefs that the condition will have a negative impact on one's life. In the two scales of *personal control* and *treatment control*, higher scores represent positive beliefs about personal control and effectiveness of treatment over the illness. In the *illness coherence* scale, higher scores represent a greater perceived personal understanding of the condition, and in the *emotional representation* scale, higher scores represent negative beliefs that the condition will affect one's emotional well-being.

Measurements of illness perception have focused on patients recovering from MI (Petrie et al. 1996; Aalto et al. 2005; Cherrington et al. 2004; Whitmarsh et al. 2003) as well as patients with other diagnoses such as multiple sclerosis (Spain et al. 2007), fibromyalgia (van Ittersum et al. 2009), and rheumatoid arthritis (Moss-Morris & Chalder 2003). In the present study, the scores of MI patients were compared to patients with diabetes type-2 (Searle et al. 2007), patients who had undergone coronary artery bypass grafting (Hermele et al. 2007), patients with a chronic kidney disease (Fowler & Baas 2006) and patients with recently diagnosed heart and neck cancer (Scharloo et al. 2005).

Multidimensional Fatigue Inventory-20 (MFI-20)

Fatigue was assessed using a Swedish version (Furst & Ahsberg 2001) of the Multidimensional Fatigue Inventory (MFI-20) (Smets et al. 1995). This is a domain-specific 20-item self-report instrument covering five dimensions of fatigue; *general fatigue* concerns the person's reports about functioning; *physical fatigue* refers to physical sensation related to the feeling of tiredness; *reduced activity* refers to a possible consequence of fatigue like decreased activity; *reduced motivation* describes the person's lack of motivation or initiative, and *mental fatigue* refers to cognitive symptoms, such as having difficulty concentrating. Each dimension is measured using four items, and

the response categories range from 1 (no fatigue) to 5 (very fatigued). A higher score indicates a higher level of fatigue. The timeframe concerns fatigue experienced during the preceding days.

The MFI-20 has demonstrated good validity and reliability in patients undergoing radiotherapy, patients with chronic fatigue syndrome, cancer patients, psychology students, medical students, army recruits and junior physicians (Smets et al. 1995). The translated Swedish version of the MFI-20 has been tested for internal consistency on 81 Swedish cancer patients undergoing radiotherapy. Cronbach's alpha for each MFI-20 factor shows good internal consistency (range 0.75-0.94). In the present study, Chronbach's alpha ranged between 0.70-0.88.

The reliability of the Swedish version has also been tested in patients with Fibromyalgia and Chronic Widespread Pain, indicating that the MFI-20 is a reliable tool for assessing degree of fatigue (Ericsson & Mannerkorpi 2007). The present results are compared with reference values from the general population (Smets et al. 1998) and other clinical populations with chronic heart failure and rheumatoid arthritis (Falk et al. 2006; Rupp et al. 2004).

Hospital Anxiety and Depression Scale (HADS)

Anxiety and depression were assessed using the Swedish version of the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983). The HAD scale is a self-administrated 14-item scale measuring depression and anxiety. This questionnaire was developed specifically for use in medically ill populations as it excludes questions about bodily symptoms. All items are scored on a four-point response scale ranging from 0-3. The summary scores for *anxiety* (7 items) and *depression* (7 items) range from 0-21, with higher scores indicating higher depression/anxiety. Each respondent could be grouped according to a clinically tested classification of psychiatric morbidity. A scale score <8 is in the normal range, a score of 8-10 classifies as a possible depression and a score of 11-21 indicates a probable depression (Zigmond & Snaith 1983). Good reliability has been reported in several studies, including MI (Martin et al. 2003).

Short Form-36 (SF-36)

Health-related quality of life (HRQoL) was measured using the generic questionnaire Short Form-36 (SF-36) (Sullivan et al. 2002). The SF-36 is a 36-item questionnaire, grouped into eight multi-item domains of HRQoL: *Physical Functioning* (PF), *Role Limitations due to Physical problems* (RP), *Bodily Pain* (BP), *General Health* (GH), *Vitality* (VT), *Social Functioning* (SF), *Role limitations due to Emotional problems* (RE) and *Mental Health* (MH). The 36 items included are summed and converted to scales ranging from 0 (worst health) to 100 (best health). It is also possible to compute summary measures of physical and mental health - the *Physical Component Summary* (PCS) and the *Mental Component Summary* (MCS) (Sullivan et al. 2002; Ware et al. 1994). The Swedish version of the SF-35 has been psychometrically tested and validated in a Swedish normal population (Sullivan & Karlsson 1998).

The Somatic Health Complaints Questionnaire (SHCQ)

The Somatic Health Complaints Questionnaire (SHCQ) addresses 13 somatic problems common in coronary heart disease patients. It consists of four scales: breathlessness, fatigue, pain and unrest (Brink et al. 2007). Respondents are asked to report how often the listed symptoms had occurred during the past week. Each question is answered on a 6-point Likert scale, ranging from never (1) to always (6). In the present study, the two scales *breathlessness* (2 items) and *pain* (4 items) were used. Chronbach's alpha was computed and ranged between 0.70-0.89.

Data analyses

Constant comparative analysis (I, II)

Data collection and analysis were carried out simultaneously, in line with a grounded theory approach (Glaser & Strauss 1967; Strauss & Corbin 1998; Charmaz 2006). One main purpose of the constant comparative method is to explain and seek relationships in qualitative data, thereby building up a theoretical understanding that can explain the collected data (Charmaz 2006). The data analyses in Study I and II can be described in two phases, initial and focused coding, in line with a constructivist grounded theory approach (Charmaz 2006). The initial coding, the line-by-line coding, is close to the data and guided by questions such as 'What is being expressed here?' and 'What does it mean?'. In the next step, segmentation of the data into smaller incidents or codes was carried out. Codes were identified and labelled according to their meaning and the actions gathered in the data. Comparisons of differences and similarities were made continuously, and initial codes were labelled and sorted into tentative categories. Categories were labelled abstractly based on the phenomenon they represented, and they were described in relation to the meanings and actions found in the data. Data collection progressed concurrent with this initial analysis and coding process. During focused coding, the most significant codes were selected. Through comparison of properties between categories, relationships among the various categories were sought. One initial conceptual picture explaining the relationship between categories was developed by relating categories and processes of "what's going on". During this process, the core categories (two core categories in Study I and one in Study II), which all categories were related to, developed. A pattern was examined and categories were refined and saturated using additional information acquired by conducting further interviews and by recoding available data: theoretical sampling. The aim of theoretical sampling is to fill any gaps and holes in the emerging theory (Charmaz 2000). This part of the analysis was primarily inductive, but also deductive when new data were gathered. The conceptual model was developed simultaneously. Sample selection was terminated when new data ceased to add anything new to the emergent model. During the entire process, theoretical reflections, questions and ideas based on the data were written down in memos. A description of the analysis is presented in Figure 2. The interpretation of the studied phenomenon is itself a construction, as is the resulting theory (Charmaz, 2006).

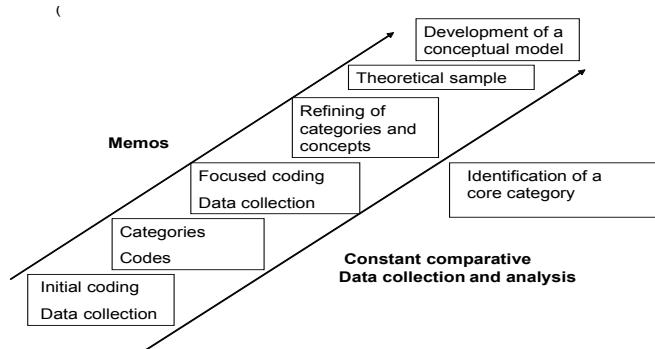


Figure 2. Description of the development of conceptual models in Study I and II.

Statistical analyses (III, IV)

Statistical analyses were conducted using SPSS for Windows (version 15 and 16.0). Parametric and non-parametric tests were compared. Because no major differences were found, the results of the parametric tests are presented. All tests were two-tailed and statistical significance was set at the 5% ($p < 0.05$) level. Descriptive statistics were performed to characterize the sample. Frequencies and percents were calculated for categorical variables, means and standard deviations (SDs) for continuous variables. Differences in the distribution of baseline characteristics were examined using chi-square tests for categorical variables and independent *t*-tests for continuous variables. In Study III, when mean scores for fatigue among patients with MI were compared with a general sample, and other clinical samples, *t*-tests were used. Changes in fatigue between first week post-MI and after four months (Study III) and in illness perceptions (IPQ-R) (Study IV) were tested using paired *t*-tests. To explore the relationships between depression and fatigue and to examine the incidence of fatigue without depression, the total group was divided into four groups according to their levels on the *general fatigue* dimension of the MFI-20 and the *depression* scale of the HADS, respectively. These cut-off values were set to the median of the actual sample, ≥ 12 , on the *general fatigue* dimension of the MFI-20 and the recommended cut-off levels of ≥ 8 on the *depression* scale of the HADS. Reliability was tested using Cronbach's alpha coefficient. In order to find possible relationships, Pearson correlations were performed on all variables of interest.

ETHICAL CONSIDERATIONS

The research project was approved by the Research Ethics Committee at Göteborg University (Dnr: 333-02). The subjects were informed, both verbally and in writing, about the aim, utility and confidentiality of the study. In addition, the letter contained information stating that the participants would receive a new request to continue in the study 4 months after MI and that some of them would also be invited to an interview about 4 months after MI. Written and informed consent were obtained from those who decided to participate in the investigation. All participated voluntarily. They were told that they were free to discontinue at any time without giving a reason. Approval from the board of the clinics was also obtained. All data will be presented without possibilities to identify any of the participants. No impact on the relationship between patients and care providers can be expected, because the researcher is not connected to the participants' clinic.

RESULTS

The findings from the different studies are presented in a mixed form, i.e. both from a qualitative perspective (Study I, II) and from a quantitative perspective (Study III, IV). Figure 3 gives an overview of the methodology and included variables in the four studies.

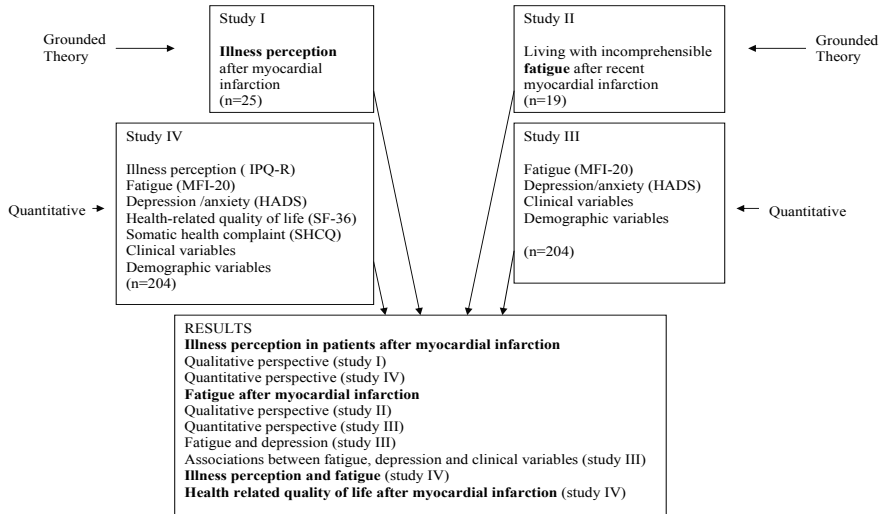


Figure 3. Overview of design and included variables in the four studies of the thesis.

Demographic and clinical data

Study I and II

The study population in Study I consisted of 25 patients (16 men and 9 women). The mean age was 58 years for both men and women (range 38-78). PCI was performed in 18 patients (12 men and 6 women). Three men had undergone CABG. Four of the patients received no intervention, neither with PCI nor with CABG. The study population in Study II consisted of 19 patients (11 men and 8 women). The mean age was 58 years for men and 61 years for women (range 38-78). All subjects in this group had a summed score higher than 15/20 on one or several of the dimensions included in the MFI-20.

Study III and IV

The study population consisted of 204 patients (145 men and 59 women). The mean age was 64 ± 10 years for both men and woman. One hundred and twelve patients (55%) had compulsory schooling only. Most of the patients were cohabiting (68%), however significantly more females were single living ($p < 0.05$). A Q-wave was found in eighty-eight patients (43%). Mean of troponin-T (Tnt) was $3(\text{SD}=6.9)$ $\mu\text{g/L}$, and for C-reactive protein (CRP) $18.2 (\text{SD}=46)$ mg/l . Fifty-six patients (28%) had a left

ventricular ejection fraction less than or equal to 40% (EF ≤ 40%). No significant differences between men and women were found for Q-wave, Tnt, CRP or EF. Percutaneous Coronary Intervention (PCI) was performed in 144 patients (71%), with no gender differences. Seven men (7%) had undergone Coronary Artery Bypass Grafting surgery (CABG), but no women. For most of the patients (76%), it was their first MI. This was true for both genders. Hypertension (36%) was the most prevalent co-morbidity, followed by diabetes (22%), angina pectoris (13%), heart failure (7%), depression (7%) and stroke (4%).

Illness perception in patients after myocardial infarction (I, IV)

Illness perception - Qualitative perspective (I)

In Study I, qualitative analysis of semi-structured interviews with 25 informants revealed a theoretical model, describing characteristics of patients' illness perception of having an MI (Figure 4). The core categories *illness reasoning* and *trust in oneself* vs. *trust in others* seem to be fundamental to viewing MI either as an acute isolated heart attack or as a sign of a chronic condition. The variations in illness reasoning were related to differences in reflectiveness, classified in 'personal terms', 'general terms' and as 'less reflective'. Informants who were reflective in 'personal terms' re-

		Trust in oneself	Trust in others
I L L N E S R E A S O N I N G	Reflective in personal terms	Sign of chronic condition – feasible to influence	Sign of chronic condition – uncontrollable
	Reflective in general terms	Acute event that can recur – feasible to influence	Acute event that can recur – uncontrollable
	Less reflective	Unthinkable acute event	Non-recurring acute event

Figure 4. A conceptual model describing variation in illness perception of myocardial infarction related to *illness reasoning* and *trust in oneself* versus *trust in others*.

ported deep and careful thinking about their illness. Achieving a deep understanding of the whole situation was important as well as searching for causal explanations for their MI. However, some of the informants who were reflective in 'personal terms' experienced troublesome thoughts and pondered about the future and how life would turn on, rather than about causes and consequences. Informants who were reflective in 'general terms' devoted some time to thinking about their illness and reasoned more generally about possible factors that could cause a heart attack and also about the consequences. These informants tried to identify factors to prevent further events but were satisfied with a general and less detailed understanding of their individual situation. Symptoms reminded them about their illness, but in between time they preferred to not think about it. Being 'less reflective' meant that the individuals did not devote time to thinking about their recent MI. Thoughts were more superficial and intermittent, and they did not wish to delve deeply into thoughts about the causes and consequences of their MI. Being 'less reflective' also involved having steadfast, fixed thoughts based on predetermined ideas that are difficult to influence.

The second core category was bipolar with the endpoints trust in oneself vs. trust in others. Individuals who had trust in themselves believed in their own ability to influence and control illness and to prevent further heart attacks. These individuals were also engaged and participated in their own health-related behaviour and recovery. Managing the illness consequences in their own way was desirable. To have an extreme trust in themselves and a marked need to be in control, could appear in mistrust regarding treatment strategies, prescript drugs and also scepticism regarding health care professionals. Individuals who trusted in others were less active and less motivated to improve their health situation on their own. They had less confidence in their own ability to control their illness, and instead they preferred to trust in the actions of powerful others, such as health care professionals and relatives. Combinations of variations in these core categories resulted in six categories illustrating variations in illness perceptions of MI: (i) 'sign of a chronic condition - feasible to influence'; (ii) 'sign of a chronic condition – uncontrollable'; (iii) 'acute event that can recur – feasible to influence'; (iv) 'acute event that can recur – uncontrollable'; (v) 'unthinkable acute event' and (vi) 'non-recurring acute event' (Figure 4).

Illness perception - Quantitative perspective (IV)

Illness perception compared with other patient populations

The *timeline dimension (acute/chronic)* on the IPQ-R, indicating patients' beliefs about the duration of their illness, differed between MI patients and other reference populations. The patients with MI perceived their illness as more acute compared to patients with type 2 diabetes and patients with chronic kidney disease. However, they perceived their illness as significantly more chronic compared to patients with CABG and patients with head and neck cancer. Patients with MI believed that their illness had fewer *consequences* in life compared to patients with CABG, patients with chronic kidney disease and head and neck cancer, but more consequences compared to patients with type 2 diabetes. Concerning the *personal* and *treatment control* dimensions, patients with MI reported lower sense of personal control as well as treatment control compared with patients with CABG - and those with type 2 diabetes. However, compared to patients with head and neck cancer, they had a higher sense of

personal and treatment control. Patients with MI reported significantly lower personal control and higher treatment control compared with patients with chronic kidney disease. Patients with MI showed a less coherent understanding (*illness coherent*) of their illness compared with patients with CABG, but a more coherent understanding compared with patients with chronic kidney disease and head and neck cancer. No differences were found between patients with MI and patients with type 2 diabetes concerning the coherence of their understanding of their illness. Patients with MI reported a lower emotional impact (*emotional representation*) of their illness compared to patients with CABG and patients with head and neck cancer and chronic kidney disease, but a higher emotional impact compared with patients with type 2 diabetes.

Changes in illness perceptions over time

The scores on the *timeline* dimension on IPQ-R changed significantly over time. One week after the MI, the patients perceived their MI more as an acute event compared to as a more chronic and cyclic after four months. Patients also changed their perception significantly to more negative beliefs about *personal* and *treatment control*. For the dimensions of *consequences*, *coherence* and *emotional representation*, no changes in perceptions were observed. Between women and men, differences were only found for the *cyclic timeline*, i.e. after four months women perceived their condition to more cyclical in nature than men did (Table 2).

Table 2. Comparison of IPQ-R dimension of illness perception between first week and four months and between genders at four months (*t*-tests)

IPQ-R dimensions	First week	Four months	Women	Men
	Mean (SD)	Mean(SD)	Mean(SD)	Mean(SD)
	n=202	n=202	n= 58	n=142
Timeline (acute/chronic)	18.14 (5.18)	20.01 (5.39)***	19.30 (4.66)	20.31(5.65)
Timeline (cyclical)	11.97 (2.7)	10,80 (2.89)***	11.93(2.78)	10.29(2.81)***
Consequences	18.40 (4.07)	18.18 (4.61)	18.38(4.60)	18.10(4.63)
Personal Control	22.33 (3.46)	21.26 (3.94)***	20.53(4.00)	21.56(3.88)
Treatment control	19.57 (3.38)	18.08 (3.22)***	17.88(2.84)	18.16(3.37)
Illness coherence	17.31 (4.17)	17.12(3.92)	17.42(3.74)	18.11(4.0)
Emotional representation	16.32 (4.58)	16.65(4.80)	16.73(4.40)	16.62(4.97)

IPQ-R; Illness Perception Questionnaire-Revised

*** p<0.001

Fatigue after myocardial infarction (II, III)

Fatigue-Qualitative perspective (II)

The identified core category was labelled *incomprehensible fatigue*, which consisted of several properties: *different kind of tiredness, unrelated to effort, unpredictable occurrence, and unknown cause* (Figure 5). The fatigue was incomprehensible because it was difficult for the individuals to identify it or relate it to a cause. The experienced fatigue was contrasted to the “usual” or “normal” tiredness, and was described as another type of tiredness that restricted their bodily, cognitive and emotional function-

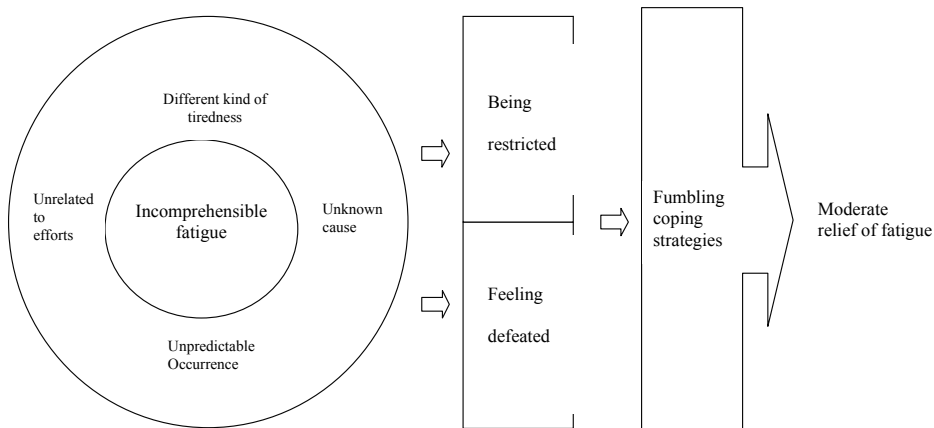


Figure 5. Living with incomprehensible fatigue after myocardial infarction

ing. Only a few of the informants attributed their fatigue to their recent MI. Unpredictable occurrence was also a property related to incomprehensible fatigue because excessive tiredness could occur during unexpected situations. The fatigue was also unrelated to efforts or to activity or exertion, and some patients could wake up after a night's sleep still feeling fatigued.

The consequences of fatigue were described in the two categories: *being restricted* and *feeling defeated*. The informants were restricted from doing the same activities they used to do, also in relation to daily routine work such as housekeeping, gardening, driving the car and for some participants, returning to work. The restrictions included bodily sensations such as heavy legs and numbness in one's arms. Intellectual functioning was restricted, including an inability to concentrate, to read the newspaper or the text on television. Overwhelming fatigue also restricted patients' motivation, creativity and initiative. The informants avoided social activities owing to the unpredictable nature of fatigue, which gave feelings of insecurity. The feeling of being defeated was related to situations in which the fatigue became overwhelming and impossible to manage. Feelings of powerlessness and exhaustion emerged suddenly, and patients were unable to manage the situation. The informants tried to manage their fatigue using different coping strategies, both temporary strategies and a combination of approaches. However, they were fumbling with strategies to cope with the fatigue. It was difficult to comprehend and often hard to manage, but only temporarily relieved by different types of strategies.

Fatigue - quantitative perspective (III)

Comparisons with reference populations

Compared with the general population, patients with MI scored significantly higher four months after MI on all MFI-20 dimensions. However, compared with patients with chronic heart failure, they reported significantly lower scores on all MFI-20 dimensions except for the *mental fatigue* dimension. Compared with patients with rheu-

matoid arthritis, the patients with MI scored significantly lower on the dimensions *general fatigue* and *reduced motivation*, but higher on the dimensions *reduced activity* and *mental fatigue*. There were no differences between these latter groups on the *physical fatigue* dimension of the MFI-20.

Changes in fatigue over time

From the first week to four months after the MI, it was found that fatigue levels decreased significantly (Table 3) on all MFI-20 dimensions (*general fatigue*, *physical fatigue*, *reduced activity*, *reduced motivation*, and *mental fatigue*). When comparing scores across gender, it was found that the women scored significantly higher on the *mental fatigue* dimension during the first week after MI. However, after four months, no significant differences were found between men and women.

Table 3. Fatigue at baseline and at four months (total sample)

MFI-20 scale	Mean(SD)	Mean(SD)	P-values ^a
	Time 1	Time 2	
General Fatigue	13.2(4.3)	12.3(4.3)	0.010
Physical Fatigue	13.2(4.5)	11.9(4.7)	0.000
Reduced Activity	12.8(4.5)	12.1(4.5)	0.031
Reduced Motivation	9.8(3.8)	8.9(3.5)	0.001
Mental Fatigue	10.8(4.0)	10.2(3.8)	0.013

^apaired samples t-test

Fatigue and depression (III)

The mean score for depression, using the HADS, was 5.0 ± 3.7 during the first week after the MI and 4.5 ± 3.6 after four months. Thirty-two patients (15.7%) were classified as possible cases of depression (HADS depression score 8-10) and ten patients (4.9%) as probable cases (HADS depression score ≥ 11) after four months. It was also shown that patients with possible/probable depression (n=42) scored significantly higher on all MFI-20 dimensions. When the total group was divided into four groups according to their scores below or above the median level (± 12) on the *general fatigue* dimension of the MFI-20, and below or above 8 on the *depression* scale of the HADS, the largest group identified were those patients who could be classified as non-depressed and non-fatigued (45%). The second largest group identified were those who could be classified as non-depressed but fatigued (33%). A smaller group of patients could be classified as fatigued with depression (19%) (Figure 6). However, in a search for differences between these groups, no variables were found that could be systematically associated with this group classification.

Associations between fatigue, depression and clinical variables (III)

All five MFI-20 dimensions showed significant positive correlations with HADS *depression* and *anxiety* measured after four months. Age correlated significantly only with the *physical fatigue* dimension (positively), and CRP showed significant positive

	< 12 MFI-20 General Fatigue	≥ 12 MFI-20 General Fatigue
<8 HADS Depression	n=92 (45%)	n=67 (33%)
≥8 HADS Depression	n=3 (1.5%)	n=39 (19%)

Figure 6. The total sample divided into four subgroups based on scores on the HADS depression scale and the MFI-20 General Fatigue scale (missing n=3; 1.5%).

correlations with both *physical fatigue* and *reduced motivation*. No significant correlations were found between the MFI-20 dimensions and troponin-T (Tnt). However, all five dimensions were significantly and positively correlated with the SHCQ scales of *pain* and *breathlessness*. Beta-blocker medication (β -blocker) was significantly correlated with *physical fatigue* (positive), but no correlations were found with ejection fraction (EF).

Illness perception and fatigue (IV)

The associations between patients' illness perceptions (IPQ-R) and fatigue (MFI-20) were examined (Table 4). All IPQ-R dimensions were significantly correlated with the MFI-20 dimensions, although *general fatigue* and *physical fatigue* were not correlated with *illness coherence*. The dimensions *timeline* (*acute/chronic* and *cyclical*), *consequences* and *emotional representation* showed positive correlations with all dimensions on the MFI-20. Thus, fatigued patients tended to expect their illness to be longer in duration and a more cyclical in nature. They also perceived more serious consequences and had more negative emotional beliefs. Personal and treatment control were negatively associated with all dimensions on the MFI-20, indicating that higher levels of fatigue were related to lower levels of personal and treatment control. Finally, weak negative correlations were found between the fatigue dimensions *reduced activity*, *reduced motivation*, *mental fatigue* and *illness coherence*, i.e., the less one's perceived understanding of the illness, the more one experience fatigue.

Table 4. Correlations between illness perceptions (IPQ-R) and fatigue (MFI-20)

IPQ-R	Time line	Timeline	Consequences	Personal control	Treatment control	Illness coherence	Emotional representation
	acute,chronic	cyclical					
General fatigue	.297***	.261***	.428***	-.257***	-.297***	-.052	.381***
Physical fatigue	.358***	.269***	.497***	-.350***	-.388***	-.062	.363***
Reduced activity	.282***	.275***	.448***	-.320***	-.350***	-.169*	.363***
Reduced motivation	.159*	.208**	.293***	-.322***	-.319***	-.217**	.357***
Mental fatigue	.182*	.238**	.384***	-.190**	-.195**	-.140*	.364***

IPQ-R; Illness Perception Questionnaire-Revised. MFI-20; Multidimensional Fatigue Inventory. * p<0.05;** p<0.01; ***p<0.001

Health-related quality of life in patients after myocardial infarction (IV)

Patients with MI scored significantly lower on all scales of the SF-36, except on *Body Pain* (BP), compared to an age- and sex-matched reference group of a Swedish general population (Sullivan et al. 2002). When men and women were compared with the reference population separately, it was found that the men scored significantly lower on all scales except BP, and that the women scored significantly lower on all scales except BP and *General Health* (GH). The only significant difference in HRQoL between men and women with MI was that women scored significantly lower on the *Physical Functioning* (PF) dimension than men did.

The following significant correlations were found between illness perception (IPQ-R) and the PCS (physical health) and MCS (mental health) scores (Table 5): The more patients perceive their illness as chronic and cyclical in nature (*timeline* dimension *acute/chronic* and *cyclic*), and the more they believe that the condition will have *consequences* in their life, the lower are their scores on PCS and MCS. The more *personal* and *treatment control* patients believed that they had over their illness, the higher the degree of PCS: and the more treatment control, the higher the degree of MCS. Positive associations between *illness coherence* and PCS were found. Moreover, the greater emotional impact (*emotional representation*) patients associate with their illness, the lower the degree of MCS and PCS. Further, as shown in Table 5, both the PCS and the MCS were negatively associated with fatigue, as well as with depression and anxiety. Finally, the greater the symptoms of pain and breathlessness, the lower the degree of PCS and the MCS scores.

Table 5. Correlations between SF-36, Physical Component Score (PCS), Mental Component Score (MCS), fatigue (MFI-20), depression and anxiety (HADS) and pain and breathlessness (SHCQ)

	PCS total	MCS total
IPQ-R		
Time line acute/chronic	-.309***	-.199**
Timeline /cyclical	-.355***	-.293***
Consequences	-.468***	-.457***
Personal control	.472***	.127
Treatment control	.460***	.207**
Illness coherence	.160*	.051
Emotional representation	-.282***	-.493***
MFI-20		
General fatigue	-.556***	-.538***
Physical fatigue	-.700***	-.497***
Reduced Activity	-.94***	-.567***
Reduced Motivation	-.430***	-.496***
Mental fatigue	-.450***	-.539***
HADS		
Depression	-.491***	-.649***
Anxiety	-.308***	-.593***
SHCQ		
Pain	-.461***	-.486***
Breathlessness	-.580***	-.335***

The main findings in summary

- The core categories illness reasoning and trust in one self vs. trust in others were found to be fundamental in viewing MI either as an acute isolated heart attack or as a sign of a chronic condition.
- Patients' illness perceptions changed from first week to four months, from viewing the MI as an acute event to as a more chronic and cyclic condition. Beliefs about personal and treatment control of MI decreased.
- Patients with MI reported lower sense of personal and treatment control compared with patients with coronary artery by pass grafting (CABG) and patients with type 2 diabetes.
- Patients levels of fatigue decreased after four months, but were still higher compared with the general population. Four months after MI, 45% could be classified as non-depressed and non-fatigued, but 33 % reported fatigue without co-existing depression.
- The central theme among those who experienced fatigue was living with incomprehensible fatigue. Because the patients could not understand why and when fatigue would strike, they fumbled when trying to cope with it.
- Illness perceptions and fatigue were correlated. Fatigued patients expected a longer duration and a more cyclic nature of their MI, lower personal and treatment control, more consequences and less perceived understanding of their illness.
- Negative illness perceptions, fatigue, depression, anxiety and symptoms of pain and breathlessness were associated with lowered HRQoL.

DISCUSSION

Illness perception after myocardial infarction

Acute event or a sign of a chronic condition

After being stricken with MI, individuals tend to view their illness in different ways. There was a distinction between viewing the MI as a delimited acute event and viewing it as a sign of a chronic condition. The informants' viewpoints also differed in degree of reflectiveness about their condition and whether they put trust in themselves or in others. Those who were reflective in personal terms perceived their MI more as sign of a chronic condition: they devoted more time to identifying possible causes and desired a detailed understanding of their illness. These results are in line with earlier research by Wiles and Kinmonth (2001), who suggested that patients may benefit from understanding the underlying disease process, as this may encourage them to adhere to healthy lifestyle changes. Also, it has been found that identification of a known cause was related to attendance to cardiac rehabilitation, and the belief that the illness was caused by an underlying atherosclerosis, rather than an isolated heart attack, was related to more commitment to healthy behaviour (MacInnes 2005).

According to the Common Sense Model of Self-Regulation, when patients face a health threat such as MI, they form cognitive illness representations (Leventhal et al. 2001). These beliefs may in turn strongly influence emotional responses, particularly if the patient blames him-/herself for the illness (Petrie & Weinman 2006). Individuals in the present thesis who were less reflective perceived their MI more as a delimited acute event. They declined causal attributions and instead preferred to "switch off" thoughts about their illness. Perhaps this behaviour can be explained as a form of denial, which has been suggested to have positive effects on mental health when the individual feels overwhelmed and lacks the resources to cope (Lazarus 1983). However, denial can also be related to non-compliance with care and treatment regimens (Levine et al. 1987).

Assessment of illness perception (IPQ-R) showed that scores on the *timeline* dimension increased after four months, indicating a change in patients' perceptions of MI from an acute illness towards a chronic condition. The majority of patients (71%) had undergone PCI during the acute illness onset, which has been established as an effective treatment for coronary artery disease and is also commonly associated with acute symptom relief and shorter hospital stays (Stenstrand et al. 2006). The hospital stay for these informants varied between an extremely short hospital stay of 2 days to 15 days. Such acute treatment including early hospital discharge may mislead patients to think about the illness as an acute heart event rather than a sign of a chronic condition.

Astin (2008) and colleagues found that patients who were intervened with PCI tended to see their treatment as curative. Given this acute care, treatment and early discharge, which make things seem fairly 'easy', it may be difficult for patients to understand the chronic background of coronary artery disease and the seriousness of the situation. Thus, the change towards viewing the illness as more chronic could reflect a more

realistic view of the illness, perhaps based on fatigue and other symptom experiences. Alternatively, patients' perceptions could also be altered after attending a cardiac rehabilitation programme.

Having a realistic illness perception seems to be better in terms of self-management of the illness. Alm-Roijer et al. (2006) found that specific, compared with general knowledge of risk factors, was positively associated with self-reported lifestyle changes in patients with coronary heart disease. Also, patients who participated in structured patient education increased their perceived knowledge, reduced anxiety and symptom severity more than did those who received written information (Ringstrom et al. 2008). On the other hand, it is also important to be aware of the sometimes beneficial effects of avoidant coping or denial (van Elderen et al. 1999). Aspects of avoidance may be seen as positive illusions. According to Taylor and Brown (1994), people's perceptions of self and the world are positively biased, and these positive illusions may promote psychological well-being. Therefore, in nursing interventions with the purpose of increasing adherence to lifestyle changes, achieving a balance between increased knowledge about risk factors and maintaining a positive and optimistic standpoint should be considered. Also, according to the present results, nurses could put more effort into educating patients who are less reflective and have trust in others than into educating patients who are more reflective and have trust in themselves.

Control

The view that one can prevent recurrence through one's own efforts was labelled as having *trust in oneself*. This was in contrast to having *trust in others*, e.g. to being less engaged and less likely to participate in treatment and recovery. Trust was ascribed to external factors such as medical treatment, health-care professionals and medical interventions. According to Rotter's (1966) social learning theory, individuals who expect their behaviour to influence outcomes are defined as having an internal locus of control, while those who expect outside forces, such as a powerful other or chance, to have the greater influence have an external locus of control. However, our results showed that individuals with an extremely strong trust in themselves expressed scepticism of health-care professionals. This is in line with the findings of Theorell et al. (2005), who suggested that neither the extreme internal nor the extreme external locus of control is optimal. According to them, it is preferable to try to move patients towards a moderate internal locus of control.

The IPQ-R asked about perceptions of personal and treatment control of the illness itself; i.e. "I have the power to influence my illness" and "The course of my illness depends on me" and "My treatment will be effective in curing my illness". The present results showed that patients' illness perceptions moved towards more negative beliefs about personal control and treatment control from the first week to four months after MI. The MI patients in the present study scored lower on personal control compared with patients with type 2 diabetes and patients with chronic kidney disease. They also perceived their illness as more chronic and had lower perceived control compared to patients who had undergone CABG. These results are in line with earlier research showing that patients undergoing PCI were more uncertain than patients who had been treated with CABG surgery (White & Frasure-Smith 1995). This is important

to consider, as earlier research has also shown that feelings of perceived control are important for recovery after a cardiac event. Patients experiencing high control were less anxious, less depressed, less hostile and had better psychosocial adjustment than did those with low control (Moser 1995). Also, negative views of MI (e.g., not controllable, long lasting, and severe consequences) have been found to be associated with more complications during hospital stays (Cherrington et al. 2004), and with greater likelihood of developing depression episodes during the first year (Dickens et al. 2008). Similarly, persons who responded to their illness by establishing a sense of control had a reduced risk of a new cardiac event (Helgeson & Fritz 1999). In addition, French et al. (2006) performed a meta-analysis to examine whether illness perception could predict attendance at cardiac rehabilitation. Their results showed that patients with more cure/control, consequences, and coherence beliefs were more likely to attend cardiac rehabilitation programmes.

Fatigue after myocardial infarction

Post-MI fatigue is a problem for patients in their daily life activities. The identified core concept “incomprehensible fatigue” may provide some new understanding of why it is difficult to cope with post-myocardial infarction fatigue. It was found that the patients felt they could not understand the unpredictable occurrence of fatigue and also that fatigue was unrelated to effort. They could not predict why and when fatigue would strike them, and therefore they fumbled when trying to cope with it. They had no entirely effective self-care strategy to use, and the result was moderate, rather than complete relief of fatigue. Patients also pointed out that this post-MI fatigue was a “new” feeling compared to pre-MI experiences of tiredness. This finding is in line with results from a study of post-MI fatigue in older women, which reported that the fatigue they perceived was different from what they had experienced prior to their MI (Crane 2005).

As could be expected on a group level, the fatigue decreased on all dimensions of the MFI-20 from the first week to four months after MI. In comparison with a general population, patients with MI scored significantly higher on the MFI-20 even after four months. After four months, MI patients are generally expected to have returned to their normal daily life. However, earlier research has shown that MI seems to restrict many patients from continuing in working life. Slightly more than half of those who were ≤ 59 years of age, and not pensioned were considered able to work two years after MI (Hamalainen et al. 2004). An interesting research question is to what extent post-MI fatigue contributes to these low figures?

The underlying causes of post-MI fatigue are not clearly understood. The aetiology could have a physiological basis (damage to the heart muscle, altered electrical and neural transmissions or threatened immune system), but could also be related to stress and coping responses. After an MI, many factors are conceivable stressors for the individual. The MI threatens patients' ordinary life with insecurity, fear of recurrence and death, lack of knowledge about heart disease, as well as difficulties in interpreting symptoms (Kristofferzon 2006). Hypothetically, fatigue could be a stress response (Olson 2007) triggered by general adaptation syndrome (GAS), where stressors result in a triphasic response of alarm, resistance (adaptation) and exhaustion (Selye 1952).

Perhaps this view, according to which post-MI fatigue could be seen as a declining ability to adapt to stressors that occur during the resistance phase of the general adaptation syndrome (GAS), could be applied to patients after MI. Note, however, that not all patients experience fatigue after their MI. According to Lazarus (1966), stress is determined by the individual's perception of the situation as stressful. Individuals differ in their reactivity to stress and ability to cope, although the process involves an individual cognitive appraisal of the demand-capability imbalance. The individual's perception of control, predictability of outcome and past experience are also important factors for stress experiences.

Fatigue and depression

Depressive symptoms are common in patients with MI (Barefoot et al. 2003; Spijkerman et al. 2005; Ziegelstein et al. 2000; Ziegelstein 2001). However in the present study the depression scores measured by the HADS were relatively low, both one week and four months after MI. Instead it seemed that fatigue was more common among our patients. Symptoms of fatigue and depression overlap (Irvine et al. 1999), and may be different expressions of the same phenomenon (Wojciechowski et al. 2000). In the present thesis, depression and fatigue were positively correlated, implying that depressed patients with MI also experienced fatigue. However, in our data, we found a sizeable group of patients (33%) who experienced fatigue without coexisting depression. This result supports the conclusions of McGowan et al. (2004), who suggested that fatigue may be experienced by some patients with MI, without coexisting depression.

Fatigue and illness perception

The present results showed that almost all dimensions of fatigue were related to illness perceptions, such that fatigued patients had a more chronic perception of illness, more beliefs in severe consequences of the illness, and beliefs about decreased personal and treatment control. However, the causal relations are unclear: Does fatigue influence illness perceptions (the more fatigue, the more negative the illness perceptions) or is the reverse interpretation more correct (negative illness perceptions create more fatigue)?

Health-related quality of life after myocardial infarction

In the population under study, patients with MI scored lower on almost every subscale of HRQoL four months after MI, compared to a general population. This is in line with earlier research on patients with MI, showing a reduction in HRQoL compared to the general population (Schweikert et al. 2008). Norekval et al. (2007) also showed that female MI survivors had poorer physical health compared with a general population. Daily activities, work capacity, mobility and energy were limited, and these women experienced more pain, discomfort, fatigue and dependence on medical treatment. Moreover, four months after MI, lower degrees of physical health were associated with patients' illness perception, e.g. the illness was thought to be more chronic, to have more consequences, and patients experienced weaker personal and treatment control. Fatigue is fairly often experienced by people who live with chronic illness,

and it may influence daily activities and quality of life negatively (Kralik et al. 2005). One year after MI, fatigue was a predictor of decreased HRQoL (Brink et al. 2005). In the present study, both the mental (MCS) and the physical (PCS) component of the SF-36 were negatively associated with fatigue.

METHODOLOGICAL CONSIDERATIONS

To obtain a broader understanding of patients' illness perception and fatigue after MI, a multi-method design was used including a combination of qualitative and quantitative methods (Morse 2002). In Study I and II, the aims were to explore illness perception and to gain a deeper understanding of what fatigue meant to patients after an MI. Given the subjective nature of illness perceptions and fatigue, constructivist grounded theory (Charmaz, 2006) was used. This method focuses on understanding 'a process' and socially constructed meanings that form the realities of people's lives. Rather than starting with a theory to explain a phenomenon, the model emerges from the collected data. The results of the present studies were based on a number of subjects in western Sweden, and are representative of the population from which they were derived. According to Charmaz (2006), qualitative criteria - *usefulness*, *credibility*, *originality* and *resonance* - for evaluating GT were formulated. The results are *useful* in a coronary care unit context. However, given the great variation in the sample and the in-depth, semi-structured interviews, the developed models account for variations in the experiences and perspectives of participants, and therefore the model may be transferable to populations with other conditions as well. The same reasoning applies to the description of the consequences of fatigue.

The criterion *credibility* refers to confidence in the truth of the data and interpretation of them. The analyses in Study I and II were carried out in parallel with the interviews, through a constant comparative analysis, in which categories and concepts are compared until no new properties yield further insights. All interviews were digitally recorded and transcribed, and memos were written down, which may have minimized the risk for inaccurate interpretations. To achieve good interpersonal contact and a comfortable atmosphere, the informants decided on the place for the interviews, which were most often conducted in their own home. Another aspect of credibility could be the process of reflecting critically on oneself as a researcher and the interaction with the participants. This aspect is called reflexivity (Hall & Callery 2001). No analysis is neutral. According to a constructivist perspective, the researcher and participants construct the data through an on-going interaction (Charmaz 2005). Despite researchers' claims of neutrality, researchers do not come to studies uninitiated, and different possible interacting effects of the researcher need to be considered. The participants in both studies (I and II) were interviewed by the first author, whose educational and theoretical background, thus whose pre-understandings are based on a nursing science perspective. This may have influenced the present theoretical understanding of the studied phenomena of patients' illness perception and their experience of perceived fatigue.

In both qualitative studies new insights are gained. This refers to the quality criterion *originality*. The work gives a deeper understanding of how patients' illness perception of their recent MI was related to different degrees of reflectiveness and trust in themselves versus others. It is important to stress that the model does not categorize the individuals themselves, but rather variations in their perceptions of their recent MI. A further finding that could entail the *originality* was the deeper understanding of

what suffering from fatigue meant for the patients. Finally, the last quality criterion, *resonances*, can be mirrored in rich descriptions of categories (in Paper I and II), with accompanying citations that illustrate patients' experiences.

In Study III and IV, validated measures were used to assess patients' perspectives on illness perception, fatigue, emotional distress, physical symptoms and health-related quality of life. Reliability was measured using Cronbach's alpha coefficient, and the values were generally found to be acceptable. To enhance generalizability, consecutive inclusion of patients was performed over a period of one year. One limitation is that the comparisons of illness perceptions (and fatigue) with other patient populations must be interpreted with caution, as they are not matched for demographic and clinical background variables. However, we found it important to give at least some reference values showing whether patients with MI tended to score higher or lower than other groups. In the present thesis, there is a limited focus on gender differences. First, in studies using qualitative methodology it is not appropriate to draw conclusions about differences between men and women. Second, in measurements of fatigue and illness perceptions, only small differences were recognized. There are probably more gender differences to explore, and investigating such aspects will be a challenge for future research on post MI-fatigue and illness perception

CONCLUSIONS AND CLINICAL IMPLICATIONS

Starting from the patients' perspective, the present thesis has described the characteristics of illness perception and experiences of fatigue in a sample of patients with MI. Moreover, the prevalence and relationships between illness perception and fatigue, clinical and demographic variables, depression, anxiety and HRQoL have been described.

Identifying an individual patient's unique illness perception could promote a better understanding of his/her illness reasoning, which in turn could give nursing staff the opportunity to individualize secondary preventive advice. It is also logical to assume that patients with different degrees of reflectiveness concerning their illness need individually adapted knowledge that is presented in an understandable way. It is not just a matter of what information is provided, but it is also of great importance how the information is presented. Understanding the way in which individuals perceive their illness may affect the type of information and education they need. Perhaps health care professionals should concentrate more resources on individuals who are less reflective about their illness, who view their MI as an acute non-recurring event, and who place most of their trust in the actions of powerful others or in e.g., medication. Such views tend to be related to less active and less self-driven rehabilitation. Using the IPQ-R could be a tool in understanding how patients 'make sense' of their illness, but it also allows quantitative analysis of changes in patients' illness perception over time.

The present study showed that a negative view of MI - i.e. that the illness is not controllable or curable, that it is chronic, and has severe consequences - was associated with worse experiences of fatigue and lowered HRQoL. We found that viewing an illness as chronic was associated with reduced beliefs in personal control. It is plausible that individuals choose to cope in ways consistent with their understanding of their illness and their resources. For example, those who believe that their illness can be controlled probably adapt more positively to illness consequences. It was found that beliefs in personal and treatment control decreased over time. Therefore, a challenge for healthcare professionals will be to help patients maintain or even increase their perception of control so that patients will have faith in medical treatment and lifestyle changes.

The results also showed that fatigue decreased after four months. Nevertheless, compared to the general population, the patients with MI perceived higher levels of fatigue. Because the patients had problems understanding why they felt fatigue and when it would strike, they fumbled when trying to cope with it. They had no coping strategies available, and the result was moderate relief from fatigue rather than complete recovery. Further, fatigue was associated with depression, although 33% of the sample reported fatigue without coexisting depression after four months. Higher degrees of fatigue, depression, anxiety, pain and breathlessness were associated with lower degrees of self-rated mental and physical health. Compared to an age- and sex-matched population, patients with MI scored lower on almost every scale of the SF-36 four months after MI.

The results also indicate that fatigue after MI should be attended to. Coronary caring staff can play an important role in screening and identifying patients with symptoms of fatigue. Considering the present findings, both fatigue and depression should be assessed separately so as to exclude the overlapping effects. It is important to identify depressed patients for adequate treatment, but it is also important to identify patients who are fatigued without coexisting depression in order to prevent the progression of worsening fatigue or exhaustion. Interventions that may lead to recovery from fatigue should be included in rehabilitation programmes, and this could start by focusing on reducing stressors and increasing patients' abilities to resist stressors.

FURTHER RESEARCH

Despite improvements in acute medical MI treatment, the results of the present thesis showed that many patients perceived their MI in ways that may hinder effective rehabilitation and lifestyle changes. It was also found that a considerable number experienced fatigue after four months. It is possible that the rapid and short treatment that is common today may be one cause of this. Further research in the following areas should be of interest:

- To investigate how the meaning of the acute event and very short hospital stays affect illness perception in patients with MI.
- Interventions to test whether altering/maintaining illness perceptions (toward more personal and treatment control) in patients with MI is related to adherence to advice on lifestyle changes.
- To clarify the underlying cause and development of fatigue after MI.
- To identify and reduce stressors as well to try to increase patients' ability to cope with stressors that may cause fatigue and exhaustion.
- To find variables that can explain why some individuals are fatigued, but not depressed.
- To explore to what extent post-myocardial fatigue may be related to adherence to secondary preventive strategies.
- Longer follow-ups of fatigue: What is the situation after 2 years (data collection terminated).

SVENSK SAMMANFATTNING

Huvudsyftet med denna avhandling var att undersöka patienters egen uppfattning av att ha haft en hjärtinfarkt samt upplevelser av uttalad trötthet efter hjärtinfarkt. Ett ytterligare syfte var att undersöka relationer mellan sjukdomsuppfattning och trötthet med depression, ångest och hälsorelaterad livskvalitet.

Behandling av akut hjärtinfarkt har genomgått stora framsteg under de senaste decennierna, vilket bland annat har resulterat i ökad överlevnad och förkortade sjukhusvistelser. För patientens långsiktiga prognos är sekundärpreventiva strategier av stor vikt. Emellertid är följsamheten inte alltid optimal till rekommenderade livsstilsförändringar och deltagande i rehabiliteringsprogram. Hindrande faktorer kan vara patientens sjukdomsuppfattning, trötthet eller depression.

I avhandlingen studerades 204 patienter som behandlats för hjärtinfarkt. Under de första dagarna på sjukhuset, samt efter fyra månader efter hjärtinfarkten fyllde patienterna i frågeformulär som handlade om den egna sjukdomsuppfattningen, uttalad trötthet och depression/ångest. Vid det andra frågetillfället besvarades också formulär om hälsorelaterad livskvalitet.

Av de aktuella patienterna kontaktades 25 stycken för en intervju som handlade om hur de uppfattade sin hjärtinfarkt (studie I). Den metod som användes var Grounded Theory. Resultatet av intervjuerna visade på stora variationer i sjukdomsuppfattning. Hjärtinfarkten kunde uppfattas som en akut isolerad händelse eller som ett tecken på en kronisk underliggande sjukdom. De olika uppfattningarna utgick ifrån graden av reflektion. En del patienter ville inte alls tänka på hjärtinfarkten, medan andra ville fördjupa sig kring frågor om orsak och samband. Den andra grundläggande faktorn som påverkade sjukdomsuppfattningen var om man hade tillit till att själv kunna påverka sin sjukdom, detta i motsats till dem som snarare hade tillit till externa faktorer (tex. behandling, närstående eller, mediciner).

I studie två intervjuades 19 uttalat trötta patienter fyra månader efter hjärtinfarkten med syfte att få en djupare förståelse för hur tröttheten upplevdes, vad trötthet innebar och hur de klarat av att hantera följderna av detta symptom. Även i denna studie tillämpades Grounded Theory. Resultatet av analyserna ledde fram till ett centralt tema: *”Att leva med en obegriplig trötthet”*. Tröttheten upplevdes som obegriplig, eftersom den var en *”annorlunda”* trötthet, inte relaterad till ansträngning, oförutsägbart överrumplande och utan känd orsak.

I studie tre svarade 204 patienter på frågeformulär rörande förekomsten av uttalad trötthet och depression under första veckan och efter fyra månader. Resultatet visade att tröttheten hade minskat efter fyra månader, men var fortfarande högre i jämförelse med en generell svensk population. Symptom på depression och trötthet överlappade, men 33% rapporterade uttalad trötthet utan samtidig depression. Inga könsskillnader hittades efter fyra månader.

I studie fyra analyserades svaren på frågeformulär som berörde den egna uppfattningen av sin hjärtinfarkt samt hälsorelaterad livskvalitet. Resultatet visade att patienternas sjukdomsuppfattning förändrats från första veckan till fyra månader efter hjärtinfarkten. Från att ha uppfattat hjärtinfarkten som en akut händelse förändrades detta till att se den mer som en kronisk sjukdom. Uppfattningen att kunna kontrollera sjukdomen själv eller genom behandling minskade också. Dessa uppfattningar, samt också att sjukdomen orsakade konsekvenser i patienternas liv, hade också samband med en högre grad av trötthet och minskad hälsorelaterad livskvalitet.

Sammanfattningsvis bidrager denna avhandling till en ökad förståelse för hur patienter upplever sin hjärtinfarkt, samt att trötthet är ett betydande symptom som påverkar patientens dagliga liv negativt. Individualiserade sekundära vårdstrategier kan börja med att identifiera patienters unika sjukdomsuppfattning. Det är också viktigt att identifiera patienter som är uttalat trötta med eller utan samtidig depression för adekvat behandling men också för att förhindra progression av trötthet till utmattning.

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