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# **Sleep-Wake-Activity and Health-Related Quality of Life in Patients with Coronary Artery Disease**

**and evaluation of an individualized non-pharmacological programme  
to promote self-care in sleep**

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*To Kent, Ida & Elin*

*"Sleep is not a waste of time"*

Chaput JP, 2009

*"Sleep, like insomnia, is not just about what happens at night:  
it's about what happens to the day"*

Green G, 2008



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# ABSTRACT

Sleep is a basic need, important to physical and psychological recovery. Insomnia implies sleep-related complaints, such as difficulty falling asleep, difficulty staying asleep, early awakening, or non-restorative sleep (NRS) in an individual who has adequate circumstances and opportunity to sleep. Insomnia is also related to impairment of daytime functions. The prevalence of reported sleep disturbances varies between 15% and 60% in patients with coronary artery disease (CAD) up to five years after intervention. Disturbed sleep may have a negative impact on self-care capacity and behaviours. Little attention has been given to evaluation of sleep promotion through individualized non-pharmacological interventions among CAD patients.

The overall aim of this thesis was to describe the impact of sleep quality and disrupted sleep on health-related quality of life (HRQoL) in patients with stable CAD, in comparison to a population-based group. The objective was also to evaluate an individualized non-pharmacological programme to promote self-care in sleep.

Four studies were conducted during seven years, starting in 2001. Patients from six hospitals in the south of Sweden were invited to participate. In addition, an age and gender matched population-based group was randomly selected during the same period as the patients and was used for comparison with the CAD patients in two of the studies. Data was collected through interviews, self-reported questionnaires, a study specific sleep diary and actigraphy registrations. A pretest-posttest control design was used to evaluate whether an individualized non-pharmacological intervention programme could promote self-care in sleep-activity in CAD patients.

The results showed a high prevalence of insomniac CAD patients out of whom a large proportion were non-rested insomniacs. This showed that NRS is one of the core symptoms of insomnia. On the other hand there were weak or non-significant gender differences with increasing insomnia severity. Severe insomniac CAD patients displayed a two or threefold higher presleep arousal or anxiety score and were more limited in taking physical exercise than the general population. Generally low sleep efficiency (SE%) was revealed in the studies, particularly among severe non-rested insomniac CAD patients.

Among CAD patients, the individualized non-pharmacological programme to promote self-care in sleep-activity indicated improvements in sleep and HRQoL.

This thesis elucidates the importance of focusing on the individual's perception of their sleep-activity and health in their local context and supporting self-care management. Furthermore, it is of importance that nurses set individual goals together with the patient in order to increase self-efficacy to promote HRQoL.

Keywords: actigraphy, coronary artery disease, health-related quality of life, insomnia, non-pharmacological programme, nursing, self-care management, sleep-activity, sleep quality

## LIST OF PAPERS

This thesis consists of four papers, two have been published in international peer reviewed scientific journals, and two papers have been submitted. The papers will be referred to in the text by their roman numerals:

- I. Johansson A, Windahl M, Svanborg E, Fredrichsen M, Swahn E, Yngman Uhlin P, Edéll-Gustafsson U. Perceptions of how sleep is influenced by rest, activity and health in patients with coronary heart disease – a phenomenographical study. *Scandinavian Journal of Caring Science* 2007; 21; 467-475.
- II. Johansson A, Svanborg E, Swahn E, Ejdebäck J, Tygesen H, Edéll-Gustafsson U. Sleep, arousal and health-related quality of life in men and women with coronary artery disease. *Journal of Clinical Nursing* 2011; 20: 2787-2801.
- III. Johansson A, Svanborg E, Edéll-Gustafsson U. Sleep-wake-activity rhythm and health-related quality of life among patients with coronary artery disease and in a population-based sample – an actigraphy and questionnaire study (Submitted).
- IV. Johansson A, Adamson A, Ejdebäck J, Edéll-Gustafsson U. Evaluation of an individualized non-pharmacological programme to promote self-care in sleep-activity in patients with coronary artery disease - a randomized intervention pilot study (Submitted).

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Addition:

Beside the publications in this thesis, part of the material and additional findings have been presented or published

Johansson A, Ejdebäck J, Swahn E, Svanborg E, Tygesen H, Edéll-Gustafsson U. Determining insomnia and health-related quality of life in patients with a previous history of myocardial infarction and in a matched controlled group. *5th World Congress the World Federation of Sleep Research and Sleep Medicine Societies (WFSRSMS)*, Cairns, Queensland, Australia 2-6 September 2007.

Johansson A, Ejdebäck J, Swahn E, Svanborg E, Tygesen H, Edéll-Gustafsson U. Insomnia, daytime sleepiness and health-related quality of life in patients with a previous history of myocardial infarction and in a matched controlled group. *A celebration event, Med dr h c professor Afaf Meleis and Twenty Years of Nursing Science*. 29-30 Nov. 2007, Linköping.

Johansson A, Swahn E, Svanborg E, Ejdebäck J, Edéll-Gustafsson U. Insomnia and excessive daytime sleepiness in patients with a previous history of myocardial infarction. *8th Annual Spring Meeting on Cardiovascular Nursing*, Malmö, Sweden, 14-15 March, 2008.

Johansson A, Swahn E, Svanborg E, Ejdebäck J, Edéll-Gustafsson U. Sleep quality, hyperarousal, and sleeplessness behaviour in patients with a previous history of myocardial infarction. *19<sup>th</sup> Congress of the European Sleep Research Society*, Glasgow 9-13 sept 2008.

Johansson A. Sömn, stress och hälsorelaterad livskvalitet hos patienter med kranskärlssjukdom. *Forskningsfestival Skövde*, 3 mars 2011 (In Swedish).

Yngman-Uhlin P, Johansson A, Fernström A, Börjesson S, Edéll-Gustafsson U. Fragmented sleep – An unrevealed problem in peritoneal dialysis patients. *Scandinavian J Urology and Nephrology* 2011; 45: 206-215.

Johansson A, Karlsson J, Brödje K, Edéll-Gustafsson U. Self-care strategies to facilitate sleep in patients with heart disease – a qualitative study. *International Journal of Nursing Practice* 2012; 18:44-51.

# ABBREVIATIONS

AMI	Acute myocardial infarction
APQLQ	The Angina Pectoris Quality of Life Questionnaire
BMI	Body Mass Index
BP	Bodily Pain
CAD	Coronary artery disease
C-gr	Control group (IV)
CHD	Coronary heart disease
CR	Cardiac rehabilitation
CVD	Cardiovascular disease
EEG	Electroencephalogram
ESS	The Epworth Sleepiness Scale
GH	General Health
HRQoL	Health Related Quality of Life
H-scale	The Hyperarousal Trait Scale
I-gr	Intervention group (IV)
MH	Mental Health
MI	Myocardial infarction
MCS	Mental component summary
NREM	Non-rapid eye movement sleep
NRS	Non-restorative sleep
PF	Physical Functioning
PCS	Physical component summary
QoL	Quality of life
RE	Role-Emotional
REM	Rapid eye movement sleep
RP	Role-Physical
SE%	Sleep efficiency
SF	Social Functioning
SF-36	The Medical Outcomes Study, the 36-item Short-Form Health Survey
SWS	Slow wave sleep
USI	The Uppsala Sleep Inventory
VCS-8	The Vicious Cycle of Sleeplessness Scale
VT	Vitality
Well-badly	Good-bad sleep quality
WHO	World Health Organization



# INTRODUCTION

Sleep is a basic need.<sup>1</sup> Most people experience sleep problems at some point of their lives which could be due to periods of stress, changes in sleep habits, personal problems or environmental factors. If sleep problems are only temporary, they need not be worried about. Good sleep will be restored when life returns to normal. In cases of residual sleep problems, there is an increased risk of developing insomnia behaviors that maintain a reduced quality of sleep and disturbed circadian rhythm.<sup>2</sup> Circadian rhythms (about a 24-hour cycle) are controlled by physiological processes, lifestyle and environment.<sup>3</sup> Insomnia denotes difficulties to initiate and/or maintain sleep or too early awakening, combined with daytime symptoms.<sup>4</sup> Depending on definition and survey methods, insomnia affects approximately 10-50% of the general population.<sup>4-7</sup> Previous research has shown that up to 28% of patients with coronary heart disease (CHD)<sup>8,9</sup> report poor sleep quality, and there are gender differences.<sup>10</sup> However, insomnia in patients with coronary artery disease (CAD) has received comparatively little attention compared to other risk factors such as blood pressure, physical activity, diet and the lipid profile.

CAD is a major cause of premature mortality throughout Europe.<sup>11</sup> In 2008; heart attacks were responsible for 7.3 million deaths worldwide (WHO 2008). CAD is an important cause of morbidity and long term disability.<sup>11</sup> It is associated with significant physical, emotional, social and cognitive<sup>12</sup> consequences and contributes greatly to escalating costs of health care.<sup>11</sup> Epidemiological studies and randomized controlled trials have shown that a large part of this CAD burden can be prevented by lifestyle changes, risk factor management and the use of certain cardio protective drugs.<sup>11,13,14</sup> The underlying pathology is generally atherosclerosis, which develops insidiously over many years and is usually advanced by the time symptoms occur.<sup>11</sup> Many risk factors have been identified among patients with CAD. However, conventional risk factors do not explain the majority of the underlying pathophysiological mechanisms for CAD or gender differences.

Many patients with CAD experience sleep-related problems, partly due to a complex life situation with multiple determining factors. Some likely causes are related to side effects of drugs as well as the disease, resulting in poor health-related quality of life (HRQoL) outcome. Non-restorative sleep (NRS) in connection with a low degree of daytime activity, partly due to daytime tiredness and sleepiness has been reported among CAD patients.<sup>2,10</sup>

Primarily, treatment for insomnia has mainly constituted of pharmacological treatment. Studies on non-pharmacological approaches in general practice show promising results, especially when the program is combined with training on sleep, sleep hygiene, stress management and relaxation, nutritional advice and practical training with the support of nurses and physiotherapists.<sup>15,16</sup> However, little attention has been given evaluating an individualized non-pharmacological programme to promote self-care in sleep-activity in patients with CAD.

From a nursing perspective a combination of subjective and objective assessment of sleep-wake and activity is important to meet the patients' needs in their local context, as the nurses usually observe and evaluate the patients' sleep, activity and health. A similar reflection about local context is made by Craig et al.<sup>17</sup> Furthermore, based on a holistic theory of health,<sup>18,19</sup> this can serve as valuable information for developing a nursing intervention design to improve sleep-wake and activity in out-clinic patients with CAD.

Future research needs to focus on a holistic perspective, including the CAD patient's subjectively perceived sleep-wake and activity and effects of sleep loss in order to promote healthy sleep and HRQoL outcome.<sup>20,21</sup> Perceptions of poor sleep and effects of sleep loss differ between the genders,<sup>2,10</sup> pointing to a need for nursing care interventions on an individual basis to promote self-care. Education of health care professionals for targeted patient education, secondary preventive measures and supportive care may reduce the socio-economic consequences of sleep loss as well.<sup>22,23</sup>

This thesis may contribute to the body of knowledge in sleep research and secondary prevention treatment in CAD patients.



# BACKGROUND

## Sleep

Sleep is important for overall well-being. According to a behavioural definition *"sleep is a reversible behavioral state of perceptual disengagement from and unresponsiveness to the environment"* (Carskadon & Dement 2011, p 16).<sup>24</sup> ...*"Behaviorally, human sleep is characterized by reclined position, closed eyes, decreased movement, and decreased responsivity to internal and external environment. The responsiveness to stimuli is not completely absent; a sleeper continues to process some sensory information during sleep"* (Markov & Goldman 2006, p 841).<sup>1</sup>

Historically, sleep was thought to be a passive state. However, sleep is now known to be a dynamic process, and our brains are active when we sleep.<sup>1</sup> Sleep affects our physical, cognitive and mental health and is essential for the normal functioning and recovery of all the systems of our body, including the immune system.<sup>25,26</sup>

## Sleep stages and circadian rhythm

Sleep is divided into sleep cycles containing different sleep stages. Each sleep cycle takes between 90 to 120 minutes and normally there are about five sleep cycles per night. The different sleep states are called rapid eye movement (REM) sleep, and non-rapid eye movement (NREM) sleep. NREM sleep is in turn further divided into four different stages (1- 4), with stages 3 and 4 often referred to as "deep sleep" (Figure 1). When the sleep stages follow each other in a harmonious process, we have good quality of sleep.<sup>24,25</sup>

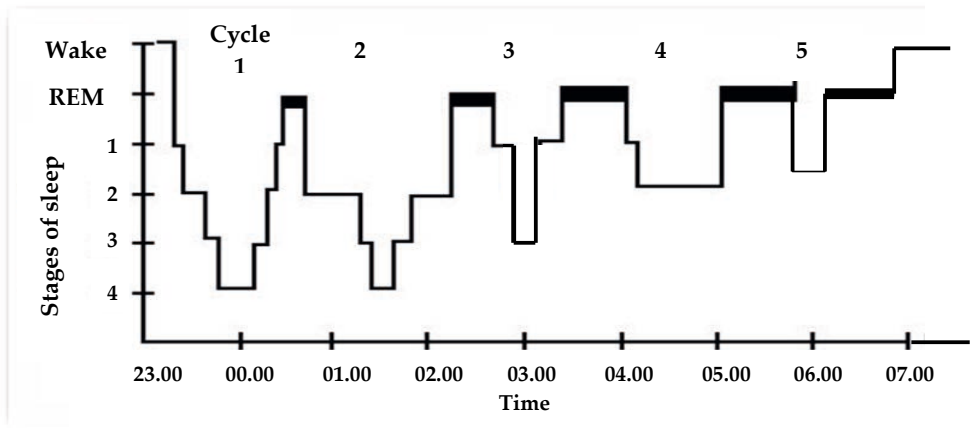


Figure 1. A hypnogram, showing the distribution of the different sleep stages during an 8-hours sleep period. REM=Rapid Eye Movement sleep (bold line).

During stage 1 the individual is in transition from a state of wakefulness to sleep. The onset of light sleep is determined by the appearance of stage 2. Stages 3 and 4 of NREM sleep are frequently subsumed by the single term slow wave sleep (SWS) referring to the slow curves indicated by the Electroencephalogram (EEG). Stages 3 and 4 are predominant during the first third of the night. REM sleep (also called dream-sleep) is marked by extensive physiological changes, such as accelerated respiration, increased brain activity, eye movement, and muscle relaxation. During REM sleep the EEG shows a pattern characteristic of an active brain, a state of relaxed wakefulness. It is prominent during the last one third of the night.<sup>1,24</sup>

Sleep quality is an important factor for our sleep and the first part of the night is important for the body to recover during sleep. Sleep duration and sleep processes change during our lifetime. People's sleep needs are individual, and linked to age. Elderly individuals have less SWS and more fragmented sleep i.e. more nocturnal awakenings and decreased ability to maintain wakefulness during the day. The amount of sleep required for young adults is about seven to eight hours.<sup>1</sup>

There is no specific sleep centre that controls our sleep, instead a number of sleep-regulating substances inhibit or promote sleep. According to Borbely's theory on sleep regulation,<sup>27,28</sup> sleep quality is determined by the combination of deep sleep (process-S) and how long the individual is sleeping (process-C, Figure 2). Sleep depth is determined by the balance between the previous night's sleep depth, how long the individual has been awake and activity level. Sleep length is determined by the circadian rhythms (biological clock).<sup>28</sup>

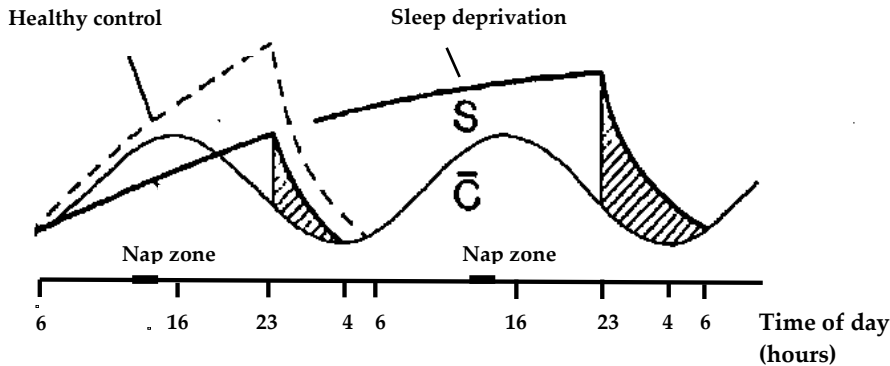


Figure 2. Sleep process-S and process-C in healthy and sleep-deprived individuals: the pressure to sleep grows stronger throughout the day as one stays awake and then disappears when one sleeps at night (shaded area for the sleep-deprived individual). Also including Broughton's (1998)<sup>29</sup> regulation of the circasemidian sleep propensity process related to nap zone. The Figure is modified and reproduced from Borbély's two-process model of sleep regulation (1987, p. 23)<sup>27</sup> with kind permission of Georg Thieme Verlag KG.

Circadian rhythms that are regulated from the Suprachiasmatic nucleus (SCN), situated in hypothalamus in the brain, control our wakefulness and alertness (sleep-wake cycle), and how fluctuations of several bodily functions recur in a cycle of about 24 hours.<sup>3</sup> SCN, the site of the circadian pacemaker is normally synchronized with the environment e.g. the daylight. Melatonin is the body's sleep hormone, which is formed in a rhythmic pattern during all hours. When we are exposed to strong daylight the formation of melatonin is slowed down and sleepiness countered.<sup>30</sup> Sleep usually follows the circadian rhythm of body temperature and is initiated when body temperature is falling. Other substances such as proinflammatory cytokines and growth hormone are hypothesized to be involved in promoting sleep and contributing to the homeostatic factor.<sup>1</sup> Cortisol that affects how tired or alert we feel is low at habitual sleep onset and high at habitual morning awakening time. Increases in platelet aggregation together with morning peaks in cortisol and catecholamine levels as well as increases in arterial blood pressure (BP) after a nocturnal nadir, are possible triggers of cardiovascular events.<sup>31</sup> The hormones leptin (satiety factor) and ghrelin (appetite stimulant) are involved in appetite regulation and energy expenditure.<sup>32,33</sup> Sleep deprivation, which is a loss of deep sleep, results in a cumulative deficit over time and is associated with negative effects on physical, psychological and cognitive functions.<sup>26,34</sup> Sleep deprivation leads to an increase in inflammatory cytokines<sup>35-37</sup> and is also

related to impairments in glucose metabolism, appetite regulation, and sympatho-vagal balance which contribute to the development of cardiometabolic disease.<sup>32,33</sup> Sleep deprivation is normally recovered by a physiological re-bounce effect e.g. prolonged sleeping times during the weekends.<sup>38</sup> In addition, total nocturnal sleep duration is an important determinant factor for recovery and waking functionality.<sup>39</sup> The circadian sleep-wake cycle has been described as a period of high and low sleep propensity. Normally we also experience a transitory period of increased daytime sleepiness around midafternoon, named nap zone, which may be explained by the circasemidian (about 12-hour) sleep propensity process visualized in Figure 2.<sup>29</sup>

## Sleep and stress

Sleep quality has a restorative function and promotes health and a feeling of well-being when there is balance between rest and sleep on the one hand and activity on the other.<sup>2</sup> A higher degree of daytime stress and presleep arousal are associated with poor sleep quality and sleep efficiency (SE%).<sup>40</sup> SE% is the ratio of nocturnal sleep duration and time spent in bed multiplied by 100. An SE% of 85% or higher is considered to be satisfactory.<sup>25</sup>

Arousal is a marker of elevated vigilance, i.e., sustained attention to specifically select information.<sup>41</sup> Arousal from sleep is described as a sudden transient subcortical or cortical activation<sup>42</sup> which may reduce the restorative power of sleep.<sup>43</sup> Arousal from sleep due to cognitive, physical and emotional events causes stress, and can be classified according to internal or external causes or stimuli which in turn result in further sleep disturbances.<sup>41,44,45</sup> Excessive psycho-physiological arousal during the day or prior to sleep (presleep arousal) may significantly delay the onset of sleep and lead to more frequent nocturnal awakenings. It is evident from previous research that sleep fragmentation leads to sleepiness-related daytime impairment assessed by objective and self-reported measurements in normal sleepers.<sup>46</sup> Furthermore, changes in mood and various adverse health outcomes have also been detected by Buysse et al.<sup>47</sup> Hyperarousal<sup>41</sup> has also been identified in other mental (emotional),<sup>7,40,48</sup> cognitive<sup>2,49</sup> and physical conditions,<sup>35,36,50</sup> resulting in a vicious circle of sleeplessness.<sup>51</sup> Vicious cycle of sleeplessness behaviour is defined *“as cognitive activities, intrusion worries, frustration, and negative expectation producing depressive reactions of sleeping difficulties, which maintain or*

*aggravate sleeplessness, in relation to one's sense of helplessness and self-efficacy in this regard"* (Edéll-Gustafsson et al 2006 p.76).<sup>10</sup>

Non-recovering sleep accumulates a sleep debt that leads to increased sleepiness, mental and physical tiredness that may progress to fatigue,<sup>26,38,52</sup> changes in dietary habits with increased energy intake,<sup>32</sup> cognitive impairment and depressive vulnerability.<sup>26,34,52</sup> The presence of fragmented sleep and non-recovering sleep are largely related to hyperreactive neurophysiological behaviours such as sleep apnea syndrome, pain, chronic fatigue, depression, etc.<sup>26,35</sup> These conditions result in daytime elevated sympathetic activity that over time results in high blood pressure, they are also associated with metabolic and inflammatory changes with increased morbidity.<sup>26,35,36,53</sup> This predicts the development of metabolic syndrome, diabetes and heart attacks,<sup>26,36</sup> which in turn leads to impaired HRQoL, increased health care costs and premature death in patients with CAD.<sup>33</sup>

Previous research indicates that patients with CAD, or patients with a recent cardiac event, experience post-traumatic stress disorder-like symptoms (PTSD).<sup>54-56</sup> The threat arises internally and results in hypervigilance to body sensations. This involves intrusive thoughts, avoidance, emotional numbing and physiological hyperarousal symptoms, for example in changes in heart rate.<sup>54,55</sup> The symptoms may be present for several months and have a negative impact on CAD patients' daily activities such as lack of physical exercise, impaired social role functioning and decreased HRQoL which contributes to the development of insomnia.

## Insomnia

Defining insomnia is a complex task, the literature contains numerous definitions.<sup>4</sup> Several epidemiological studies<sup>5,6,57,58</sup> have been conducted and depending on the definition of insomnia, i.e. insomnia symptoms, with or without daytime consequences, dissatisfaction with sleep, and insomnia syndrome, the prevalence rates vary and are reported in up to 50% of the general population. Three main classification systems offer specific diagnostic criteria for insomnia; International Classification of Sleep Disorders (ICSD-2),<sup>59</sup> Diagnostic and statistical manual of mental Disorders (DSM-IV)<sup>60</sup> and International Statistical Classification of diseases (ICD-10).<sup>61</sup> The definition of insomnia implies isolated sleep-related complaints with duration longer than one month, such as difficulty falling asleep or maintaining sleep, early morning awakening, inadequate total sleep time and non-restorative sleep

(NRS) in setting of daytime impairment e.g. change in alertness (tiredness, sleepiness), energy, cognitive function, behaviour or emotional state. With these characteristics in mind the prevalence of insomnia may be approximately 10% in the general population.<sup>62-64</sup> NRS is often described as a subjective feeling of being unrefreshed upon awakening, which may be the result of poor quality or unrestful sleep.<sup>65</sup>

Hyperarousal behavior may predispose the development of insomnia.<sup>40,62,66,67</sup> This elevated state of alertness makes it difficult to sleep and the condition may lead to reduced resilience to stress, increased vulnerability and diminishing the patient's coping capacity. In addition, it can be related to sleeplessness behaviour<sup>41</sup> with experiences of poor self-efficacy for self-care in sleep.

Regarding daytime impairment it is important to differentiate sleepiness from tiredness or fatigue. Tiredness, fatigue and exhaustion can be seen as distinct states along the same continuum.<sup>68</sup> A tired or fatigued individual does not have a propensity to fall asleep given an opportunity to do so. Physical tiredness is described as a gradual loss of energy in proportion to energy expended, tiredness is also characterized by cognitive and mental reactions such as forgetfulness and impatience. On the other hand fatigue is characterized as a decreased endurance with concentrating difficulties that are out of proportion to energy expended.<sup>68</sup> A sleepy individual is not only loss of energy, but also falls asleep given the opportunity to do so.<sup>1</sup> Daytime sleepiness is defined by Johns and Hooking as *"the propensity to doze or fall asleep when intending to remain awake and to be distinguished from subjective feelings of tiredness"* (1997 p. 844).<sup>69</sup> This also relates to the quality and the continuity of a previous night's sleep. Obstructive sleep apnea (OSA), most common among men, is associated with daytime sleepiness.<sup>70</sup> Epidemiological studies show that insomnia is associated with a decrease in HRQoL among patients with a chronic illness.<sup>21,71</sup>

Insomnia can be assessed through interviews and questionnaires to catch the patients' self-perceived sleep including medical status, medication and psychological factors. Additional information provided by a sleep diary, actigraphy and polysomnography may also prove useful.

## Cardiovascular disease

Cardiovascular disease (CVD) due to atherosclerosis is a group of disorders of the heart and blood vessels which include CAD. The most common reason is a build-up of fatty deposits in Intiman, the inner wall of the blood vessel.<sup>72</sup> This is initially a storage of lipids and inflammatory cells, followed by a progressive fibrosis development. The atherosclerosis pathological process is complex and usually develops over many years.<sup>73</sup> There is strong scientific evidence that behavioural and metabolic risk factors play a key role in the etiology of atherosclerosis (Table 1).<sup>11,74</sup> Changes in sleep activate inflammatory and metabolic processes and may over time contribute to an increased risk of developing CAD.<sup>35,36</sup> Diagnosis is based on clinical symptoms (Table 2) and diagnostic tools as including; physical examination, electrocardiogram, biochemical markers, echocardiography and coronary angiography.<sup>11,75</sup> Stable angina pectoris is a clinical syndrome usually characterized by discomfort or pain in the chest with radiation to the jaw, shoulders, back or arms. Common symptoms are also shortness of breath, tiredness and fatigue.<sup>75,76</sup>

Table 1. An overview of cardiovascular risk factors.<sup>11,74,77</sup>

Behavioural risk factors	Metabolic risk factors	Other risk factors
Tobacco use	Hypertension	Low socio-economic status
Physical inactivity	Diabetes	Age
Unhealthy diet,	Cholesterol level	Gender
Harmful use of alcohol	Overweight and obesity, especially abdominal	Inherited disposition
		Psychological factors (e.g. stress, depression)

Table 2. Classification of angina severity according to the Canadian Cardiovascular Society, CCS-class I-IV.<sup>75</sup>

Class	Level of symptoms
Class I	No limit of normal everyday activity. Angina occurs only at the strenuous, rapid or prolonged physical activity
Class II	Slight limitation of ordinary activity. Angina occurs on walking uphill or exertion after meals, in cold weather, when under emotional stress or only during the first few hours after awakening.
Class III	Marked limitation of ordinary physical activity. Angina occurs when walking at normal speed and under normal conditions in one to two blocks or climb more than one floor.
Class IV	Inability to carry out any physical activity without discomfort or angina at rest.

CAD treatment focuses primarily on reducing the incidence of acute thrombotic events and the development of ventricular dysfunction, i.e. efforts to prevent myocardial infarction and death. Percutaneous coronary intervention (PCI) and surgical revascularization (CABG) are two well-established approaches to revascularization for treatment of stable angina. The indications for myocardial revascularization and the preferred approach (PCI or CABG) depend on the extent and severity of the stenosis as identified by coronary angiography, the patient's condition and co-morbidity.<sup>76</sup> Furthermore, lifestyle changes and pharmacological treatment play crucial roles in preventing the development of the atherosclerotic disease process.<sup>11</sup> In addition, prevention is well described in international guidelines. However, no recommendations about sleep and its consequences are described.

## Cardiac rehabilitation

Cardiac rehabilitation (CR) can be described as the clinical implementation of preventive care by a professional multidisciplinary integrated approach for comprehensive risk reduction and global long-term care of cardiac patients.<sup>78</sup>

Cardiac rehabilitation was defined in 1993 by the World Health Organization (WHO)<sup>79</sup> as *"the sum of activities required to influence favourably the underlying*



*cause of the disease, as well as the best possible physical, mental and social conditions, so they may, by their own efforts preserve or resume when lost, as normal a place as possible in the community. Rehabilitation cannot be regarded as an isolated form of therapy but must be integrated with the whole treatment of which it forms only one facet.” (p1).*

Unfortunately, these days only about a third of coronary patients in Europe receive any form of CR.<sup>80,81</sup> Research shows adverse lifestyle trends and an increasing prevalence of cardiovascular risk factors in cardiac patients (Table 1).<sup>80</sup> CAD is a chronic disease, many physical, psychological, social and economic problems affect patients’ adherence to treatment recommendations throughout their lives. People with CAD and their families need the guidance of health professionals to manage the physical and psychosocial problems caused by the disease. CAD is preventable, using relatively basic and inexpensive lifestyle changes. Adding psychosocial and psychoeducational components to standard cardiology care can significantly improve QoL and reduce cardiovascular risk factors. Nurses who are part of the multidisciplinary health team play a core role in the guidance and education given to the patient’s family.<sup>82</sup>

Physical activity and exercise training are key components for CR in order to promote a better HRQoL, maintain or improve functional capacity and to be effective in reducing cardiovascular mortality.<sup>83</sup> Physical activity and physical exercise is often used as synonyms. Physical activity includes any muscular movement a human being performs that results in energy expenditure above the basal level. Physical exercise is part of a physical activity that is planned, structured, repetitive with the purpose to improve or maintain physical function.<sup>78,84,85</sup> The summary of the Swedish general health recommendations for physical activity in the prevention and treatment of disease states that: All individuals should be physically active at least 30 minutes every day. The intensity should be at least moderate e.g. fast walk. Additional health effects can be achieved by increasing the daily amount or intensity.<sup>78,86</sup>

It is important to educate and give individualized advice with regards to comorbidity, life situation related to the patient’s context and own goals.<sup>13,78</sup> Lack of knowledge of positive effects leads to difficulties with long-term adherence and problems maintaining a healthy lifestyle. A sedentary lifestyle not only increases the risk of adverse cardiac events but is also accompanied by effects on sleep quality.<sup>87</sup>

## Health, Quality of Life and Health-Related Quality of Life

The concept of health originates from the constitution of the World Health Organization, and is defined as: *"a complete state of physical, mental, social wellbeing and not merely the absence of disease or infirmity"* (WHO 2006, p1).<sup>88</sup> Since this definition was made in 1948 disease patterns have changed partly due to public health measures and more powerful health care interventions. In recent years this definition has been widely discussed. The general concept of health in this context is the need for reformulation and changing the emphasis towards the ability to adapt and self manage.<sup>89</sup>

Based on a holistic theory according to Pörn,<sup>18,19</sup> the concept of health is not based on illness but on three structured components: the repertoire (intrapersonal resources, capability and ability), the environment (internal and external) and the goals of the subject. Experiencing good health depends on the relationship between these three variables and them being in tune with the patient's context and that is when the circadian rhythm and everyday life are synchronised. It is important that the goals are realistic in relation to the individual's capabilities.

Health is a dimension of quality of life.<sup>20</sup> The World Health Organization (WHO) defines quality of life (QoL) as *"an individual's perception of his/her position in life in the context of the culture and value systems, in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns. It is a broad-ranging concept, incorporating in a complex way a person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment"* (Group TW, 1994 p. 43)<sup>90</sup>

Since QoL is a wide concept, HRQoL is often used to assess aspects of an individual's subjective experiences related both directly and indirectly to health, disability and the impact of a disease and its treatment relevant to the patient's everyday functioning.<sup>21,91</sup>

Bowling<sup>20</sup> states that it is important that the concept HRQoL rests on a concept of health as well as on quality of life. HRQoL can be measured by either generic or disease-specific instruments.<sup>92</sup> HRQoL measurements have been added as a supplement to morbidity and mortality data and are regarded as a multidimensional construct usually containing some measurements of general health, physical and mental health as well as social well-being.<sup>92,93</sup> HRQoL has become an important predictor and complementary endpoint in clinical trials, also affecting therapy choices for an ageing population.<sup>91</sup> It is

important to take the patients' assessment of their subjective health status into account.<sup>93</sup> All coronary and high risk patients have to be entitled to comprehensive multidisciplinary cardiovascular prevention and rehabilitation programmes to help them reduce their risk for cardiovascular disease and improve their HRQoL and life expectancy. Studies have indicated lasting negative effects on HRQoL following myocardial infarction, angina pectoris or other cardiac symptoms.<sup>94</sup> Both age and gender are known to have effects on HRQoL. Generally, women have a tendency to assess their health to be poorer than men and physical health decreases with higher age.<sup>95-98</sup>

Sleep disturbances can change the circadian rhythm, partly due to psychophysiological behavioural, social life changes and alterations in the immune and metabolic systems, with poor HRQoL outcome.<sup>21</sup> Assessment of HRQoL is particularly valuable in patients with CAD, as the goal of intervention is not only to extend life but also to relieve symptoms and improve function and ability to participate in daily life activities. Combining a disease-specific instrument and the generic instrument is sometimes important in order to capture the specific effects of the disease and treatments on patients and enabling a description of a broad range of states of health.<sup>21,99</sup> Based on Pörn's<sup>19</sup> holistic approach it is important to obtain knowledge about the impact of angina pectoris on physical activities, sleep, emotional state, life satisfaction and goal setting, which affect HRQoL.

## Self-care

Self-care according to Orem<sup>100</sup> has a holistic approach and is defined as *"learned, goal-oriented activity of individuals. It is behavior that exists in concrete life situations directed by persons to self or to environment to regulate factors that affect their own development and functioning in the interests of life, health, or well-being"* (Orem 2001, p. 490). Central to the concept is that self-care is an active phenomenon performed each day that is being initiated voluntarily and intentionally by an individual in concrete life situations after decision-making skills to choose an appropriate course of action. Self-care requisites, each one important to human functioning, are essential to Orem's model. Some of them are fundamental for the life processes; another is the maintenance of a balance between activity and rest which is important to avoid exhaustion or harmful stress.<sup>101</sup> Barriers to self-care may be insufficient knowledge, low adherence and unclear instructions. Functional status (cognitive impairment, mobility), psycho-social (attitudes, self-efficacy, depression, social support) and

economic factors<sup>102</sup> as well as disease specific barriers<sup>103</sup> may be indirect predictors for self-care outcome. Research has shown an association between excessive daytime sleepiness and difficulties performing self-care among patients with heart failure.<sup>103</sup> There is evidence that poor sleep impairs cognition and cognitive performance.<sup>104</sup> Our suggestion is that impaired cognition performance may interfere with self-care management. These reflections are also described by Riegel and Weaver<sup>105</sup> Self-care to promote sleep and activity among patients with CAD requires both knowledge and skill, but little attention has been given to identify how to improve the skills needed to perform adequate self-care. CAD is a chronic illness requiring continuous adaptation to healthy behaviour.<sup>19</sup>

## Self-care management in coronary artery disease

Self-management, is essential for a satisfying life and can be described as any activities that individuals do as an active participant based on their ability to promote health, disease management and enhance self-efficacy.<sup>106,107</sup> Self-care management in day-to-day living is a decision making process that requires awareness and assessment of bodily symptoms and treatments related to the CAD, i.e. self-monitoring activities.<sup>13,108</sup> According to Bandura's social cognitive theory (1995, p. 2),<sup>109</sup> self-efficacy is defined as "*the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations*". These beliefs play a key role for the outcome of self-care interventions and affect health status.<sup>13</sup> According to Pörn's<sup>19</sup> holistic view, the individual's ability to adapt is dependent on health, environment in relation to a the individual's goals.

To achieve results, education and counseling in the non-pharmacological programme must be based on the patient's perspective. "What are the individual's goals for meeting the requisite?" and "What is the person interested in and motivated and willing to do?".<sup>110</sup> Knowledge is important for the self-care process. For sufficient self-care the patients require both tactical skills (e.g. how to) and situational skill (or what to do then?).<sup>111</sup> In some patients these skills develop over time and with practice.<sup>112</sup> The majority of patients, however, need support to manage self-care skills. It is not always the case that increased knowledge will automatically lead to improved self-care. Learning requires the ability for reflection and analysis and the patients' self-

efficacy affect learning. Health professionals need to reflect on and analyze their own approach, the perception of the patient and the knowledge as well as promote a positive climate for learning.<sup>113</sup>



# AIMS OF THE THESIS

The overall aim of this thesis was to describe the impact of sleep quality and disrupted sleep on health-related quality of life in patients with stable coronary artery disease, compared to a population-based group. The objective was also to evaluate an individualized non-pharmacological programme to promote self-care in sleep.

The specific aims of the studies were to:

- I. describe how patients with coronary artery disease perceive that their sleep is influenced by rest, activity and health in outpatient care.
- II. evaluate whether there are gender differences in insomnia, sleep quality, sleep efficiency, general arousal, disease-specific and health-related quality of life in patients with coronary artery disease, compared with an age and gender matched randomly selected group from the general population.
- III. explore whether there are gender differences in sleep and health-related quality of life in patients with coronary artery disease and a matched population-based sample, and also to see how subjectively rated sleep is associated with actigraphy. Secondly, whether factors that predict patients' sleep quality could be identified.
- IV. evaluate the effectiveness of an individualized non-pharmacological programme to promote self-care in sleep-activity in patients with coronary artery disease following treatment – a randomized intervention pilot study.





# METHODS

## Design

This thesis has explorative (**I**), descriptive (**I-III**), comparative (**II-III**) and prospective (**II**) designs combining both qualitative (**I**), and quantitative (**II, III**) approaches in order to generate more knowledge from the patients' perspective to understand and identify internal and external factors essential for the nursing management of psychological supportive health care and education for patients' self-care in sleep. Knowledge from studies **I-III** was used for development of the intervention study (**IV**, Figure 3). Study **IV** had a pretest-posttest design in order to evaluate an individualized non-pharmacological programme to promote self-care in sleep. In addition a comparative design (**IV**) was also used between groups. An overview of the studies **I-IV** can be found in Table 3.

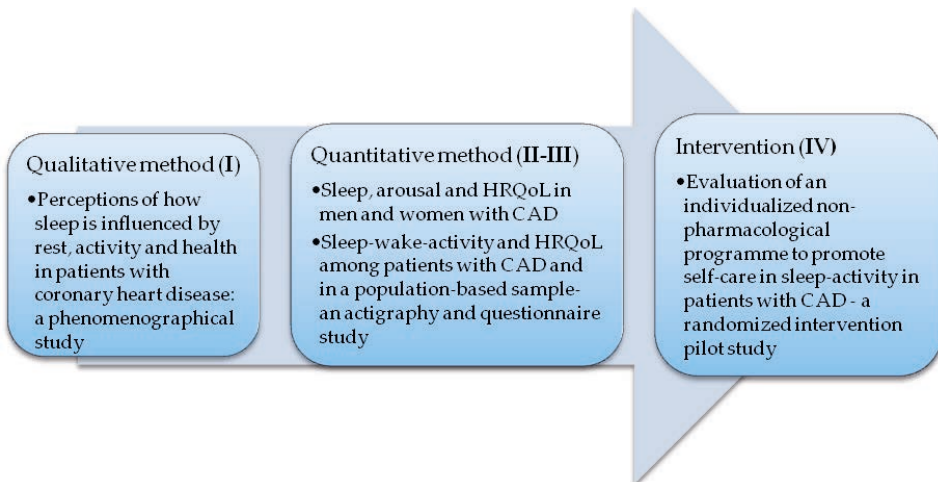


Figure 3. Based on a holistic perspective, knowledge from studies **I-III** was used for development of the intervention study **IV**.

Table 3. Overview of the design, methods and analyses in study I-IV

	Study I	Study II	Study III	Study IV
Design	Qualitative Explorative <sup>1</sup> Descriptive <sup>1</sup>	Descriptive Comparative Prospective Model testing	Descriptive Comparative	Randomized controlled Pre-test and post test Comparative <sup>1</sup>
Participants	33 patients with CHD <sup>2</sup>	556 men/ 324 women with CAD <sup>10</sup> and a matched population- based group	57 patients with CAD <sup>10</sup> and 47 from a population- based sample	47 patients with CAD <sup>10</sup>
Datacollection	Interviews	Questionnaires: USI <sup>3</sup> , ESS <sup>4</sup> , VCS-8 <sup>5</sup> , H-scale <sup>6</sup> APQLQ <sup>7</sup> , SF-36 <sup>8</sup>	Questionnaires: USI <sup>3</sup> , ESS <sup>4</sup> , SF-36 <sup>8</sup> Actigraphy Sleep diary	Questionnaires: USI <sup>3</sup> , ESS <sup>4</sup> , SF-36 <sup>8</sup> Actigraphy Sleep diary
Dataanalyses	Phenomeno- graphy According to Dahlgren & Fallsberg, <sup>118</sup>	Descriptive statistics Comparative statistics Chi-square McNemar Spearman's correlation ANOVA <sup>9</sup> Cronbach's $\alpha$	Descriptive statistics Comparative statistics Chi-square Fisher's Exact test Spearman's correlation Multiple stepwise regression Cronbach's $\alpha$	Descriptive statistics Chi-square McNemar Spearman's correlation Multiple stepwise regression Cronbach's $\alpha$

<sup>1</sup>Design only presented in the frame, <sup>2</sup>Coronary heart disease <sup>3</sup>Uppsala Sleep Inventory, <sup>4</sup>Epworth Sleepiness Scale, <sup>5</sup>Vicious Cycle of Sleepiness Scale, <sup>6</sup>Hyperarousal Behavioural Trait Scale, <sup>7</sup>Angina Pectoris Quality of Life Questionnaire, <sup>8</sup>the Medical Outcomes Study, the 36-item Short-Form Health Survey, <sup>9</sup> multifactorial analysis of variance, <sup>10</sup>Coronary artery disease.

## Participants and setting

### Study I

In study I data was collected through interviews. A purposeful sampling was used to achieve variations in the data including patients of both genders and different ages. Thirty-five patients on the waiting list to undergo or those who had undergone coronary angiography, cardiac intervention or those who had

received pharmacological treatment and patients with chest pain without verified ischemic heart disease, from two general hospitals and one university hospital in southern Sweden between February 2003 and April 2004, were invited to participate. The respondents received both verbal and written information about the study. Patients interested in participating received a telephone call to schedule an interview. Thirty-three patients were included in the study after informed consent. Patients' characteristics are shown in Table 4, p. 30.

## Study II and III

In study **II** and **III** data was collected at one university hospital and two general hospitals in the southern region of Sweden. Between January 2001 and January 2004, 1384 patients with CAD, Canadian Cardiovascular Society classes I and II (Table 2, p. 16), scheduled for coronary angiography whereof 327 women and 609 men, agreed to participate in the study. Finally, 324 women and 556 men were compared with a randomly selected age and gender matched population-based group. Flowcharts of the participants (**II**, **III**) are shown in Figure 4, p. 29. Sociodemographic and self-reported medical history for the patients and the population-based groups are shown in Table 4, p. 30.

## Patients

The patients were consecutively included and assessed by a cardiologist according to routine practice. The patients received a letter containing information about the studies (**II**, **III**), the questionnaires, an informed consent form and a postage-paid pre-addressed envelope. Two reminders were sent out within five weeks. A one year follow-up of the CAD patients' HRQOL, 265 women (81%) and 467 men (77%), was performed in January 2005.

Those who also agreed to participate in the actigraphy study (**III**) were contacted by telephone and were given verbal information specific for the study. An appointment for actigraphy recordings was organized. Thereafter the participants received a letter containing more specific information about the study as well as the actigraph, sleep diary and a postage-paid pre-addressed envelope. The actigraphy recordings and sleep diary were filled in during seven consecutive days. The participants were informed to fill in the

sleep diary in the morning and in the evening. If the participants had any questions during the recording period, they were informed to contact one of the researchers. Access to actigraphy ruled inclusion of the participants. Fifty-seven CAD patients were eligible, 32 women and 25 men. For comparison 47 participants, 21 women and 26 men from the Swedish population were included from the population-based group. In addition, an age, gender and season matched group of 29 participants were compared to the CAD patients (III).

### *A matched population-based group*

The age and gender matched population-based comparison group from the south-east region of Sweden was randomly selected in two steps. Firstly from the “Swedish Government Person and Address Register Database” during the same period as the patients, secondly from a sample of 4500 subjects, aged 18 and older. The response rate was 60%.

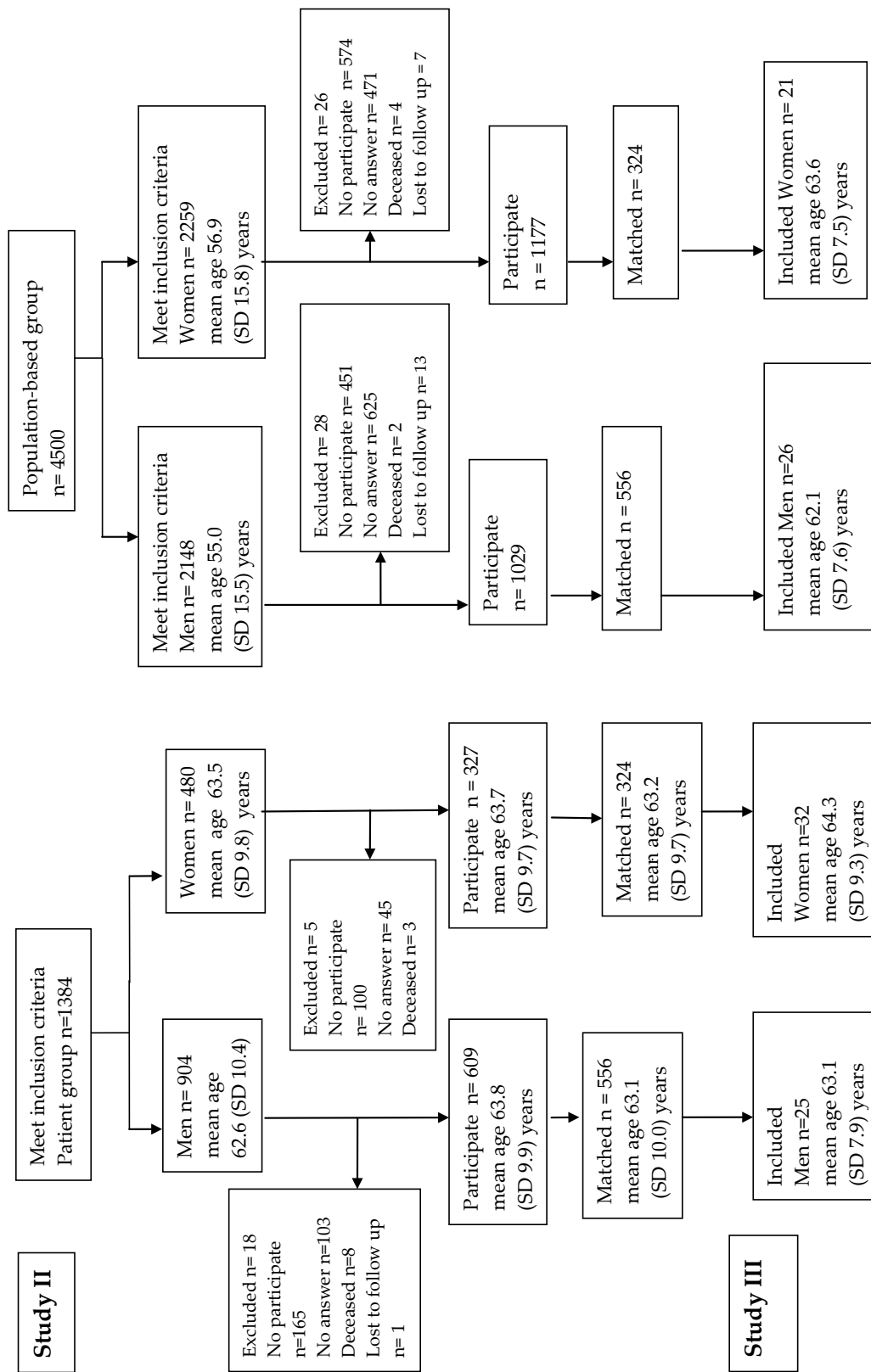


Figure 4. Flowcharts of the participants in study II and III.

Table 4. Sociodemographic and self-reported medical history for the patients and the population-based groups in study I-IV.

	Study I n= 33	Study II CAD pat/ pop-based group n=880/n=880	Study III CAD pat/ pop-based sample n=57/n=47	Study IV I-group/C-group n=24/n=23
Women	16	324/324	32/21	10/6
Men	17	556/556	25/26	14/17
Age <sup>a</sup>	61(11.5)	63(9.9)/63(9.9)	64(8.7)/63(7.5)	64(10.0)/62(11.5)
Married/ Cohabiting	29	545/686	40/34	20/21
Employed	-	304/381	33/27	10/16
<b>Self-reported disease<sup>b</sup></b>				
Hypertension	-	387/262	28/9	16/13
Diabetes	-	143/94	11/7	3/1
Joint disorder	-	177/227	21/10	9/7
Muscular pain	-	306/204	28/14	4/7
Gastrointestinal problems	-	142/166	13/9	8/7
Previous MI <sup>c</sup>	-	188/65	18/5	21/20
BMI <sup>a</sup>	-	27(4.6)/26(3.5)	27(4.3)/26(3.7)	28(4.2)/29(4.6)
Snoring <sup>d</sup>	-	424/668	19/21 <sup>e</sup>	11 <sup>e</sup> /15
Sleep apnea <sup>d</sup>	-	534/173	25 <sup>f</sup> /4 <sup>g</sup>	6 <sup>f</sup> / 6 <sup>f</sup>
<b>Self-reported pre-intervention<sup>h</sup></b>				
Coronary angiography	-	253/81	-	22/19
PCI	-	142/23	-	10/14
CABG	-	111/31	-	5/4

<sup>a</sup>Mean value (SD), <sup>b</sup>One patient can have more than one reported disease, <sup>c</sup>Myocardial infarction, <sup>d</sup>Confirmed by a bedfellow and rated 1-2 nights/week, (occasionally) to every or almost every night (very often), <sup>e</sup>1 missing values, <sup>f</sup>2 missing value, <sup>g</sup>6 missing values, <sup>h</sup>In study II, 64 patients had undergone both PCI (Percutaneous coronary intervention) and CABG (coronary artery bypass surgery).

## Study IV

In study IV data was collected in an outpatient clinic at one general hospital in the south-west of Sweden between February 2009 and February 2011. An initial screening was performed during a routine nurse follow-up appointment at the clinic 3-7 weeks after PCI, CABG and/or pharmacological treatments. The patients who reported problems with too little sleep (yes) and poor sleep quality (score  $\geq 4$ = rather bad to bad) in the Uppsala Sleep Inventory (USI) were included. The patients' characteristics are shown in Table 4, p. 30. These patients received verbal and written information about the study, an invitation to participate, questionnaires and a pre- addressed envelope to be returned within seven days. Fifty-three patients were randomized consecutively after giving informed written consent to participate in the study. A sealed envelope was drawn from a box in the department determining whether the patient would belong to the intervention group (I-group) or the control group (C-group). Both groups received medical care and check-ups according to standard treatment by a cardiologist who was blinded to group allocation. The flowchart of the inclusion process and drop-outs of patients from baseline to 3-4 month follow-up is shown in Figure 5, p. 32.

## Exclusion criteria in study I-IV

Exclusion criteria were verified diseases with poor prognoses such as a malignancy, a history of cerebrovascular disease, other neurologic diseases with sequelae or mental disorder under medical treatment. Patients with current unstable CAD, known alcohol or pharmacological abuse, and/or difficulties understanding or writing the Swedish language were also excluded. Exclusion criteria for the population based-group (II) and population based-sample (III) were difficulties understanding or writing the Swedish language, major medical disorders that made the participants unable to respond to the questionnaires and being included in the patient group.

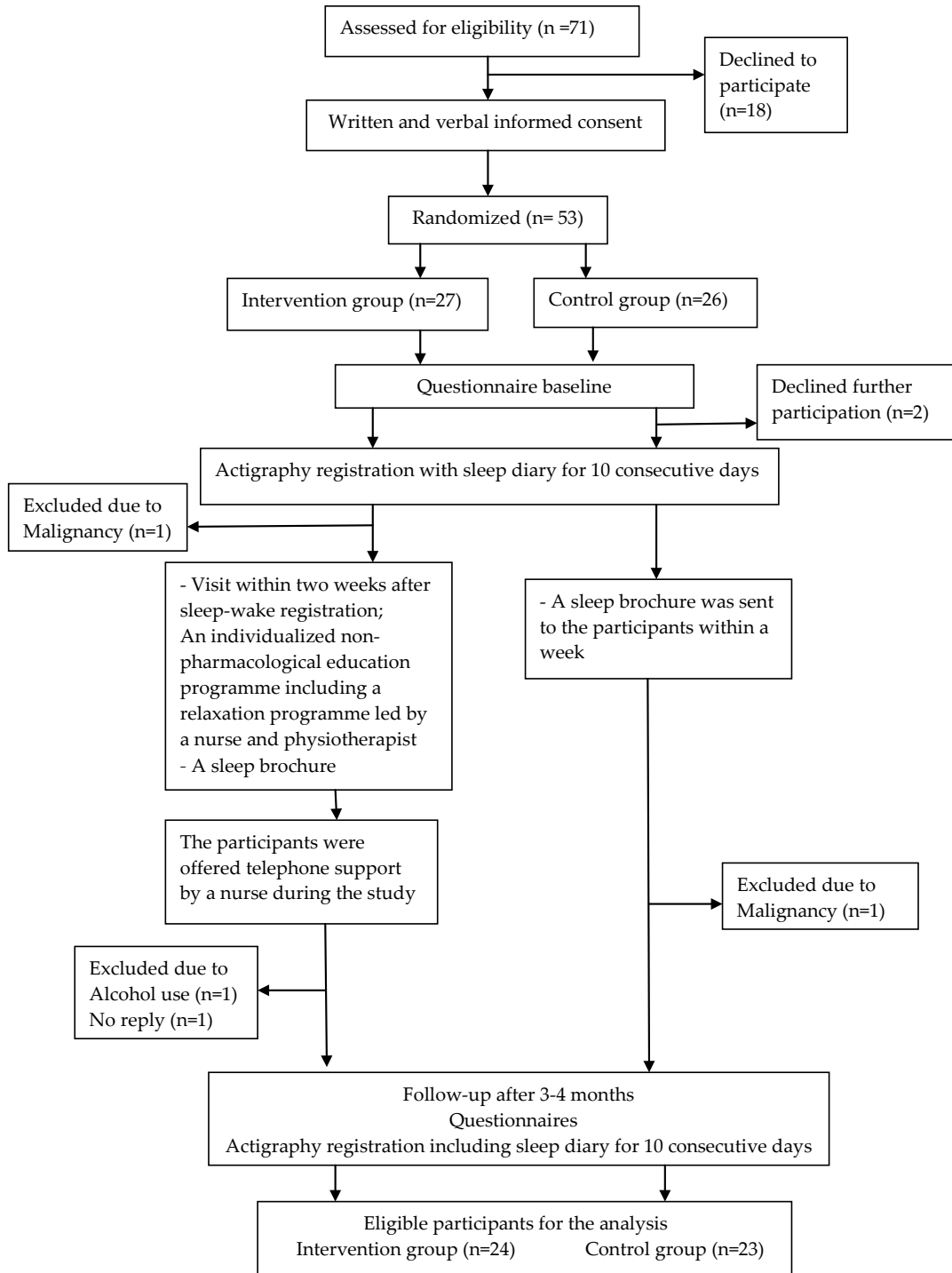


Figure 5. Flowchart of the participants' progress through the trial phase in study IV.



# Qualitative methods

## Phenomenography

Study I used an explorative and descriptive qualitative design inspired by phenomenography. Phenomenography is a research approach that has been developed within educational research in Sweden at the Department of Education at the University of Gothenburg.<sup>114</sup> In the last decades it has been increasingly used in nursing sciences.<sup>115</sup>

According to Marton,<sup>116,117</sup> phenomenography is used to discern and describe different ways of experiencing phenomena in the surrounding world. The purpose of the phenomenographic method is to capture as many existing different conceptions and experiences (what and how aspects) as possible of the phenomenon and to find the underlying structure of variance and relate it to a context.<sup>116,117</sup> Conception has a central position in phenomenography.<sup>115</sup> Marton & Booth<sup>117</sup> describe different ways to incorporate knowledge, in first order or second order perspectives. The first order perspective is about facts, what can be described in terms, that is, how something really is. In phenomenography, taking a second-order perspective is important, the researcher is primarily interested in how people experience and conceive the world around them. The researcher must consciously take a step back from his/her own experience of the phenomenon.

## Interviews

Thirty-one interviews, lasting for 30-90 minutes, were carried out at the hospital. Two interviews were held at the patients' homes. The dialogue was opened by general questions concerning demographic data, combined with questions based on an interview guide that followed phenomenographic practices<sup>118</sup> and was developed from the literature and clinical experience. The questions were about sleep and how the patients' perceived sleep patterns with rest, activity and health. Examples of questions were: *"Describe how you have been sleeping recently?"* and *"Describe how you think physical activity influences your sleep?"* The time frame was left completely open, referring to the times the patients decided themselves. At the end of each interview a short

summary was given to the respondents so they were able to correct the information if necessary. In agreement with the patients all interviews were audio-taped and transcribed verbatim. Three test audio-taped interviews were conducted before the main study out of which one was excluded due to technical problems. The author of this thesis (AJ) performed 20 interviews and two co-authors (MW, PY-U) performed 10 and 3, respectively.

## **Analysis**

To describe variations in perceptions and at the same time study certain aspects of patients' knowledge about the phenomenon,<sup>115,117,118</sup> the data analysis followed Dahlgren and Fallsberg's seven steps<sup>118</sup> (Table 5). The first researcher analyzed the transcribed interviews and then read and discussed the preliminary categories together with the co-researcher. Similarities and differences were sought after during analysis and in this way the tool became the comparison between different answers, in order to arrive at descriptive categories.<sup>119</sup> Synonymously with ways of experiencing, the descriptive categories constituted the outcome space.<sup>116</sup>

The preliminary categories were tested by a teacher, experienced in the phenomenographic method, by positioned quotations from the findings under the different categories for 10 interviews. Intersubject agreement was 95% and was considered to be satisfactory.<sup>115,119</sup> Finally, a phenomenographic researcher (MF) read the analyses in order to further specify the descriptive categories.

Table 5. The seven steps of phenomenographic analysis, according to Dahlgren and Fallsberg.<sup>118</sup>

- 
1. **Familiarization:** The material was read carefully several times and the tapes were repeatedly listened to.
  2. **Condensation:** The most significant perceptions describing the phenomenon were sought for. Even different perceptions were chosen. The perceptions were named and listed in the margin. The phase of really getting to know the material was given a lot of time.
  3. **Comparison:** The significant perceptions were compared with one another in order to identify variation between them or logical relationships to one another. The differences and similarities between the different interviews and each individual interview were subsequently compared. A goal was to find implied descriptions. 'What' and 'how' questions were posed during the analysis.
  4. **Grouping:** The perceptions were grouped into preliminary categories. This grouping was repeated several times and categories reflecting phrases, choice of words, etc. of the phenomenon emerged during the analysis.
  5. **Articulating:** A preliminary description of the essence of the different preliminary categories was made to describe the similarities and differences in descriptive categories and subcategories.
  6. **Labelling:** A linguistic expression was denoted for each of the noted categories.
  7. **Contrasting:** All the categories were compared and the unique character of each category was described, as well as similarities to the other categories.
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## Quantitative methods

### Questionnaires

Self-reported data was collected by validated and reliability tested (p. 45) questionnaires (II-IV) and a study specific sleep diary (III-IV).

The Uppsala Sleep Inventory (USI) was used (II-IV) to assess habitual sleep and perceived health during the last four weeks.<sup>10,120</sup> The USI provides data on time going to bed (p.m), sleep onset latency (time from light off to falling

asleep assessed in minutes), nocturnal awakenings (frequency), morning awakening time (a.m), sleep duration (hour and minutes), daytime napping (frequency) and sleep efficiency (SE%). Sleep efficiency was calculated as the ratio of reported nocturnal sleep duration and time spent in bed multiplied by 100 (SE%). An SE% of 85% or higher was considered to be satisfactory.<sup>25</sup> Sleep quality was defined as “*how have you slept the past 4 weeks*”, assessed on a 5-grade scale, from good (score 1) to bad (score 5). Furthermore snoring and apneic behaviour, which was confirmed by a bedfellow where scored from “never” (1) to “very often” (5). The severity of sleep problems and daytime symptoms such as difficulty to fall asleep, maintaining sleep, early morning awakening and inability to be refreshed by sleep, daytime sleepiness and physical and mental tiredness were scored on a 5-point scale from no problems (1) to very major problems (5). In this thesis the questions concerning sleep duration, the degree of sleep problems and daytime symptoms formed the basis for the operational definition of insomnia (Table 6). Socio-demography, self-reported diagnoses and pharmacologic therapy were also assessed by the USI.

**Table 6.** Operational definition of insomnia (II, IV)

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*Moderate insomnia*

- duration: more than one month of subjective complaints of one or more symptoms of:

Difficulty

- falling asleep<sup>a</sup>,
- maintaining sleep<sup>a</sup>,
- early morning awakening<sup>a</sup>

> 30 minutes of

- sleep onset
- time spent awake during the night
- early awakening before desired morning awakening time

Nocturnal sleep duration

< 6.0 hr

combined with at least one daytime symptom<sup>a</sup> of sleep loss, of not being rested by sleep, daytime sleepiness, physical or mental tiredness, respectively (Buysse et al.<sup>4</sup> 2006 p. 1157, Morin et al.<sup>5</sup> 2006 p. 124-125).

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<sup>a</sup>Moderate insomnia was score  $\geq 3$  (moderate to major complaints) and severe insomnia was score  $\geq 4$  (severe to major complaints) in the Uppsala Sleep Inventory (USI), respectively. Mild insomnia or no insomnia  $\leq 2$  (II) was defined as self-reported minor problems the last four weeks assessed by USI.

The Epworth Sleepiness Scale (ESS) was used in study **II-IV** for assessment of excessive daytime sleepiness due to the likelihood of falling asleep (rated on a 4-point scale of 0 [never] to 3 [high chance]) while engaged in eight passive or active waking activities. A summated score of 10 or higher was considered to indicate excessive daytime sleepiness.<sup>121</sup>

The 8-item Vicious Cycle of Sleepiness Scale (VCS-8)<sup>51</sup> was used (**II**) in order to assess perceived sleeplessness behaviour rated on a 4-point scale of 0 (never), 1 (seldom), 2 (sometimes), 3 (often) and 4 (always). A higher score indicates a greater problem.

The 26-item Hyperarousal Behavioural Trait Scale (H-scale) was used in study **II** to measure the specific psychological behavioural traits related to level of cortical activity and/or due to general arousal or hyperarousal proneness.<sup>122</sup> The H-scale refers to the subject's self-reported propensity to becoming introspect, thinking about feelings, responding intensely and having prolonged reactions to unexpected stimuli, as well as behaviours that involve cortical arousal, commonly self-reported by insomniacs. A more negative affective bias and inhibition of overt emotions expression, particularly social interactions refer to stressful events. This can interfere with mental and physical health.<sup>41,122,123</sup> The H-scale is a 4-point scale from 0 (not at all) to 3 (extremely). A higher score indicates a greater problem. The scale assesses a total summation score "HSUM"; Introspectiveness including six items (summated score range 0-18); Reactivity including three items (summated score range 0-9); and Extreme responses referring to a total number of items checked as extreme (score 3).<sup>41,122,123</sup>

In study **II-IV** health status i.e. health-related quality of life (HRQoL) was assessed by the Medical Outcomes Study Short Form Health Survey (SF-36).<sup>124,125</sup> This generic questionnaire consists of eight health domains; physical functioning (PF), role limitations due to physical health 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 questions relate to the last four weeks and each domain scores 0-100, where a higher score indicates better HRQoL. The eight domains are summarized in two overall health indexes; physical (PCS) and mental (MCS) component summary.<sup>124</sup>

The Angina Pectoris Quality of Life Questionnaire (APQLQ) was used to assess disease-specific quality of life in study **II**.<sup>92,126</sup> The purpose of the APQLQ is to capture the particular effects of the disease and its treatment on patients.<sup>92,127,128</sup> APQLQ has 22 items, which are divided into four scales: physical activities, somatic symptoms, emotional distress and life satisfaction.

The questions relate to the last week and each item scores 0-100. The score ranges from all of the time – none of the time, or 0 (the worst) – 100 (the best possible specific quality of life).

## **Sleep diary**

The sleep diary contained questions concerning the participants' current sleep night by night for seven (**III**) and ten consecutive days (**IV**), thus providing an overview of the participants' sleep pattern. The current sleep data was used for controlling the concordance to the actigraphy registrations (**III**, **IV**). Measured variables in the study-specific sleep diary are shown in Table 7. The study-specific sleep diary was created with support from the literature<sup>25,129</sup> and the authors' own experience from clinical work among patients with heart disease. The participants were informed to fill in the sleep diary in the morning and in the evening.

A few changes were made in the sleep diary after study **III** to suit the purpose in study **IV**. In addition, the sleep diary (**IV**) included three questions about physical performance: 1. *"During the day, did you perform any physical activity such as biking/walking?"* for less than 30 minutes (1), more than 30 minutes (2) or not at all (3), 2. *"To what degree did you feel hot/strained during your physical activity today?"* not at all (1), to some extent (2), fairly much (3) and very much (4). 3. *"To what extent did you experience anxiety/fear in connection with your physical activity today?"* not at all (1), to some extent (2), fairly much (3) and very much (4). At the 3-4 month follow-up, another question had been added: *"Has the CD-based relaxation programme improved your sleep?"* Not at all (1), to some extent (2), fairly much (3) and very much (4).

Table 7. Descriptions of measured actigraphy variables (Model AW-L, Cambridge Neurotechnology Ltd, UK) and sleep diary variables in studies **III** and **IV**.

Variables	Description	Scale
Sleep variables	Bedtime, nocturnal awakenings, wake time during the night, morning awakening time, get up time, sleep duration and daytime napping.	-
Sleep latency	The latency before sleep onset following bedtime.	Minutes
Sleep quality <sup>1</sup>	Answer the question "How did you sleep last night?"	1 (well) – 5 (badly)
Sleep efficiency (SE%)	Ratio of time in bed and nocturnal sleep duration usually expressed as: (Total sleep time/Time in bed) x 100	Acceptable value ≥85%
Fragmentation index <sup>2</sup>	The addition of Percentage Minutes Moving and Percentage Immobility. This is used as an indicator of disrupted and restless sleep.	<20=good sleep, >50=poor sleep
Wake bouts <sup>2</sup>	The actual number of episodes of wakefulness.	Frequency
Total activity score <sup>2</sup>	The total amount of activity calculated from sleep start to sleep end.	Frequency

<sup>1</sup>Registered only by sleep diary, <sup>2</sup>FI, registered only by actigraphy,.

## Actigraphy

A total of 728 (III) and 940 (IV) sleep-wake cycles were collected by actigraphy recordings from CAD patients (III, IV) and a population-based sample (III). Rest-activity patterns including indirect sleep were measured during 24-hour periods, for one week (III) and for 10 consecutive days twice (IV), using Cambridge Actiwatch with a light recorder (the Model Actiwatch-L® (AW-L), Cambridge Neurotechnology Ltd, UK (Figure 6). The actigraph is a non-invasive technique, a small device similar to a wristwatch placed on the non-dominant wrist and can with advantage be used for registration during longer periods in the home environment.<sup>130</sup> Periods of repetitive arm movements were scored as wakefulness and inactivity as sleep. Activity was measured by the piezo-electric accelerometer (Actiwatch-L®), that was set up to record the result of intensity, amount and duration of movement exceeding 0.05 g in all directions. The actigraph samples data 32 times per second and captures the highest amplitude as peak intensity of the movement in that second. The data logged is the sum of the captured counts from the individual 1-second intervals making up the 1-minute epoch and are given as the total count. The total count for an epoch is the same as activity score. If there is no activity for 1 minute the score for the epoch will be zero (Camntech Ltd.).<sup>131</sup>

The patients wrote down the times and data for putting on and removing the actigraph from the wrist in the sleep diary. Data was transferred to and analyzed by the software program Actiwatch Sleep Analysis, version 1.09.<sup>132</sup> Information about time going to bed and getting out of bed provided by the patients' sleep diaries was used to edit and calculate the actigraphy data. To validate the recording time against actual time the actigraph was pre-programmed to start at 10 am for all participants. In the sleep diary, weekdays were compared with the corresponding weekday in the actigraphy recordings, respectively.

For study IV, the patients used the same actigraph at baseline and the 3-4 month follow-up, with the exception of one patient whose actigraph disappeared. Descriptions of measured actigraphy variables are shown in Table 7 (p. 39). The individual actigram was printed and used together with the sleep diary to visualize individual sleep problems, goal setting and motivating of CAD patients (I-group) in the intervention study (IV). An actigram for 7 consecutive days are visualized in Figure 7.





Figure 6. Actiwatch-L® applied at the wrist (III, IV)

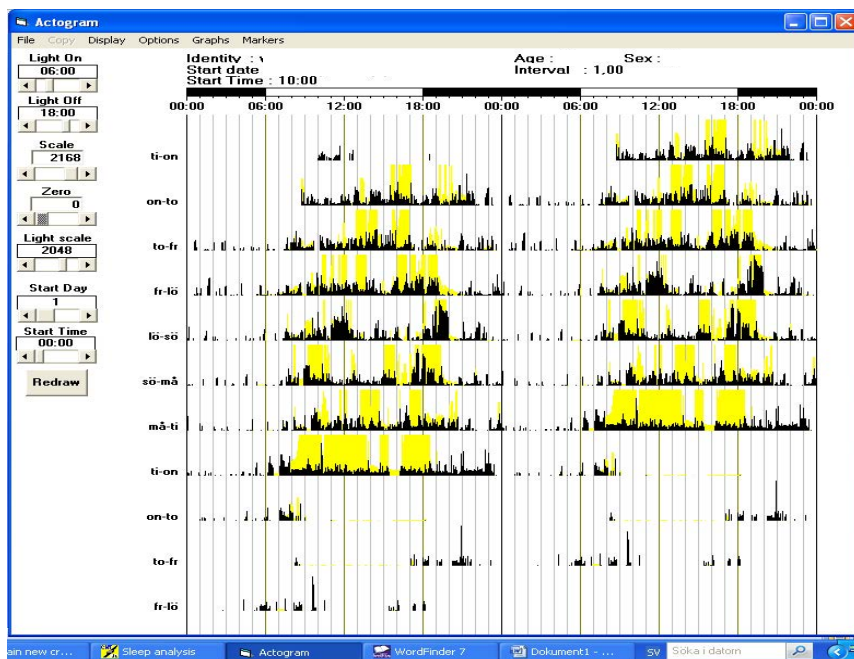


Figure 7. A screen illustration of an actigram (Actiwatch-L®), registration for 7 consecutive days.

## Intervention

The study flow of an individualized non-pharmacological programme to promote self-care in sleep-activity is shown in Figure 8.

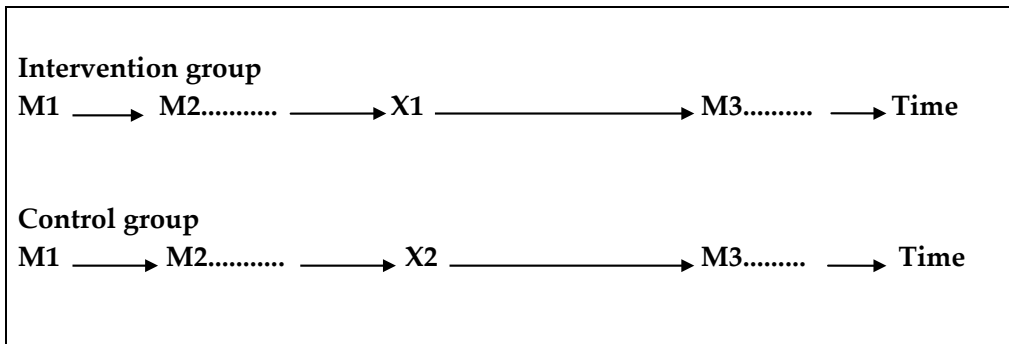


Figure 8. The flow for the time points of intervention and data collection.

**M1=** Answering questionnaires at baseline. **M1-M2** about 2 weeks. **M2=** Actigraphy registration with sleep diary for 10 consecutive days, **X1=** Visit at the outpatient clinic after actigraphy registration was performed. An individualized non-pharmacological programme to promote self-care of sleep-activity including a relaxation programme. **X2=** A sleep brochure was sent to the participants. **M3=** Evaluations 3-4 months after **X1** or **X2** by answering questionnaires and actigraphy registration with sleep diary for 10 consecutive days.

The Intervention-group (I-group) filled in the questionnaires about sleep and daytime sleepiness (**M1**). Thereafter they performed actigraphy registration and kept a sleep diary for 10 consecutive days (**M2**). This was followed by a nurse-led individualized non-pharmacological programme (**X1**) to promote self-care of sleep-activity. Individual counselling on physical training, relaxation exercise and a CD-based relaxation programme were provided by a physiotherapist. The patients were recommended to follow the advice every day. The recommended levels of physical activities were; go on for >30 minutes at moderate intensity, for example a fast walk thus following general health promotion recommendations regarding physical activity.<sup>86</sup>

The non-pharmacological programme included an individual sleep analysis related to circadian rhythm and activities. The appropriate sleep problems were partly based on the baseline data (actigraphy analysis, sleep diary) and the patients' perceived sleep and activity. Sleep habits and sleep related

lifestyle together formed the basis for setting up individual goals together with the nurse. The advice on sleep hygiene included reducing disturbing factors in the bedroom such as temperature, noise and lights. Regular sleep habits were established by actigraphy registration, the sleep diary and the patients' own perception. Through regular sleep behaviour, SE% can be increased when the need for sleep is built up by spending less time sleeping during daytime and going to bed and waking up around the same time every day.<sup>25</sup> The patients received a brochure<sup>133</sup> about sleep and stress, and were given a CD-based relaxation programme and instructions by a physiotherapist. The sleep brochure contained general information about sleep as a basic need, causes and effects of sleep deprivation, stress as a sleep disturbing factor and how to manage it and sleep hygiene – general advice for better sleep and where to turn for further advice.

All patients were offered telephone support by a nurse throughout the study. A follow-up was performed 3-4 months (**M3**) after the education programme using actigraphy, sleep diary for 10 consecutive days and questionnaires (Figure 8). It also included a self-reported evaluation of the individualized setting of goal/goals.

The Control-group (C-group) completed the same questionnaire as the I-group (**M1**), performed actigraphy registration and filled in a sleep diary for 10 consecutive days. They received the same brochure about sleep and stress as the I-group (**X2**). No individual education programme, physical training advice or the CD-based relaxation programme were given to the C-group. A second evaluation with the same questionnaires, actigraphy registration and diary was performed after 3-4 months (**M2**) (Figure 8).

To evaluate the patients' sleep, several outcome variables were selected: sleep quality, sleep onset latency/sleep latency, sleep duration, nocturnal awakenings, sleep efficiency (SE%) and number of naps. These were selected from the questionnaires and the sleep diary. Sleep duration, sleep latency, SE% and fragmentation index were selected from the actigraphy registration. In addition, health status (HRQoL) at baseline and follow-up were evaluated.

Before commencing this study the staff went on a 3-day education and training sleep programme based on Borbély's model (Figure 2, p. 11)<sup>27,134</sup> and part of Morin and Espie's clinical guide to assess and treat insomnia.<sup>25</sup> Sleep education elements, literature studies and clinical practice training were included. They also read a booklet on "How to sleep better".<sup>135</sup> Thereafter the design was tested on one patient through actigraphy recordings and a sleep diary for 10 consecutive days, respectively. These were evaluated and

discussed among the staff. The programme was led and followed-up by two members of the research group (AJ, U E-G). After the evaluation, a few minor changes were implemented and a relaxation programme was developed and tested on an equivalent patient group (AA). The responsible nurse conducted the individual specific education programme, whereas the same physiotherapist provided all instructions and physical training. The physiotherapist did not take part in the nurses' individual specific education programme.

## Statistical analyses

To achieve an appropriate sample size for gender analysis (II) with a 90% power and statistical significant level of alpha 0.01 and an effect size of 0.30/0.50, it would be required to assess 233 CAD-women and 331 CAD-men for sleep quality. However, due to gender differences regarding poor sleep symptoms, which are more common in women, the sample size of men was increased to nearly twice the number of the female sample size.<sup>136</sup> The response rate was 70%.

In the pilot study (IV) sample size was calculated for the sleep variables SE% ( $r = -0.44$ ) and for sleep onset latency ( $r = 0.45$ ) (USI) which showed a need for a sample size between 32 to 50 participants in each group for power  $\approx 0.80$ .<sup>137</sup> Occasional internal dropouts occurred at a rate lower than 5% (II). No significant dropout rate was found between baseline and the one year follow-up for gender, self-reported diseases and number of diseases, or between the three hospitals (II). For study IV internal dropouts occurred at a rate of 11%.

Data was analyzed according to the design and methods in studies II-IV. A general description of the results was provided by absolute and relative frequencies (n), per cent (%), median (Md), inter quartile range (Q1-Q3), means (m) with range or standard deviation (SD), response rate and 95% confidence interval (C.I.). The Chi-Square test (II-IV), Fisher's Exact test (III) and McNemar test (II, IV) were used for comparisons of categorical variables. Kruskal-Wallis was used for comparison of age and gender between the patients from the three hospitals (II). The Mann-Whitney U test was used for comparison between two independent groups (II-IV) with respect to continuous variables and Wilcoxon's test was used between matched groups (II, III) and within subjects (IV). In addition, in study II the SF-36 was analyzed by Student's t-test for comparison of mean scores between

independent groups and Students t-test for matched groups. Internal consistency was assessed using Cronbach's alpha (II-IV).<sup>137</sup>

In order to provide support for a model, a path analysis (study II), with several steps, was used to investigate the relationships between patients' sleep quality, SE%, arousal, VCS-behaviour and physical exercise. Associations between different variables in the first step were investigated using Spearman's bivariate correlations as several of the variables were ordinal or did not satisfy normality assumption. The variables that turned out as being statistically significant in the next step were included in a multiple model to investigate their relative contribution to the model where also covariates such as age, gender and diseases were included. A variance analysis model was used for the analysis of SE% as a continuous outcome, and for sleep quality as dichotomy outcome (0= Well or rather well, 1=rather badly or badly) a logistic regression analysis was used.<sup>137-139</sup>

Spearman's bivariate correlation was used (III, IV) to explore associations between sleep quality and different variables. The variables that turned out were in the next step included in a multiple stepwise regression analysis.<sup>137-139</sup>

Statistical tests were two tailed and alpha was set at  $p < 0.05$  (II-IV). SPSS 17.0 (SPSS Inc, Chicago, IL) (II) and 17.0 (SPSS Inc, Chicago, IL) and 19.0 (IBM statistics) (III, IV) was used for all analyses.<sup>140</sup>

## Validity and reliability

Validity and reliability are two important criteria to assess the quality of a study in both quantitative and qualitative research. There is a difference in the way they are used and the content of the concept.<sup>137</sup>

Trustworthiness is about being able to describe the research process in a systematic way, to justify knowledge produced in qualitative research.<sup>137,141</sup> The criteria used for trustworthiness are credibility, dependability, confirmability and transferability.<sup>137,141</sup>

The audio recording of the interviews increased the credibility of the transcription process. In order to strive for credibility, quotations have been added from the interviews to show the relationship between the empirical data and the categories.

Dependability refers to the reliability of data over time and by using intersubjective agreement with satisfactory result there is an increased possibility for other researchers to be able to use the categories.<sup>119</sup> In phenomenography method (I) according to Marton,<sup>116</sup> the replicability is not

justified or even desirable. The description of the categories constitutes the “discovery” of the study.<sup>115,119</sup>

Confirmability in phenomenography is about taking a second-order approach, the researcher has to be neutral and avoid colouring the findings with the pre-understanding of the phenomenon studied. At the same time, the researcher must have a certain knowledge of the phenomenon in order to distinguish its structure against the background of the situations where it can be experienced, separate its prominent features, view it from someone else’s perspective and be open to further development.<sup>117</sup> There was a satisfactory agreement between the researchers concerning the content of the categories in the study despite different experiences in the research area and methodologies.

Transferability refers to generalizing the findings to other groups and this is not essential in the phenomenography method. However, the clinical implications of phenomenography aim to give health care professionals knowledge about differences in conceiving health care-related phenomena.<sup>115</sup>

All questionnaires used for data collection in the quantitative studies (II-IV) had previously been tested psychometrically and had shown validity in other patient groups and in the general population. The internal consistency and reliability of the scales was assessed using Cronbach’s alpha (Table 8). The coefficient has a maximum value of 1 where a value above 0.70 is recommended to ensure acceptable reliability.<sup>137,139</sup>

Part of the USI questionnaire has been validated in relation to polysomnography.<sup>48,142</sup> Difficulties falling asleep and estimated sleep time in the USI are associated with sleep latency and total sleep time polysomnographic data respectively in patients with insomnia.<sup>142</sup> USI is used in epidemiological studies on the general population, the elderly<sup>143</sup> and different patient groups.<sup>10,144,145</sup> Internal consistency reliability was tested by Cronbach’s alpha (II) on the variables sleep quality, time going to bed, falling asleep and morning awakening times, nocturnal awakenings, not rested by sleep, daytime sleepiness, physical and mental tiredness (Table 8).

ESS has been well validated and reliability tested and used in a number of studies<sup>69,146-148</sup> The internal consistency reliability has showed a Cronbach’s alpha coefficient of 0.84 in the Swedish version.<sup>147</sup>

VCS-8 scale has been tested for reliability in the Swedish general population.<sup>51,41</sup>

The Swedish version of the H-scale has been tested for construct validity in the general population.<sup>41</sup> It has also been reliability tested for homogeneity

and internal consistency, the Cronbach's alpha coefficient for the total summation score (HSUM) showed 0.84.<sup>41</sup>

SF-36 has been widely used in research, it has been demonstrated to have good psychometric properties and has shown good reliability in the Swedish general population with a Cronbach's alpha between 0.79 and 0.91.<sup>125</sup> It has also been shown by Dempster and Donnelly<sup>92</sup> that SF-36 has high internal consistency coefficients and good discriminative validity for angina, post-myocardial infarction (MI) and post-cardiac surgery patients.

APQLQ has been validity and reliability tested.<sup>92,126,127</sup> The internal consistency in study **II** showed a Cronbach's alpha coefficient for the global score (Table 8) corresponding with Wiklund.<sup>126</sup>

Both actigraphy and sleep diaries are methods of measurement in sleep research and in practice. Actigraphy recordings have been validated according to polysomnography in various populations and correspond reasonably well in comparisons of total sleep time, number of nocturnal awakenings, wake time after sleep onset and sleep efficiency (SE%).<sup>130,149,150</sup>

The study specific sleep diary (**III, IV**) was created according to previously used models of sleep diaries<sup>25,151</sup> and partly validated against polysomnography and the USI.<sup>129</sup> Sleep duration, sleep latency, sleep onset and nocturnal awakenings were in congruence with polysomnography recorded sleep.<sup>129</sup>

The use of multiple methods of data collection (methodtriangulation) to describe the impact of sleep quality and disrupted sleep on HRQoL in patients with CAD gives further strength to this thesis.<sup>137</sup>

Table 8. Cronbachs'alpha scores in the questionnaires used in study II and IV included coronary artery disease (CAD) patients and a population-based group.

<b>Cronbachs'alpha</b>		
<b>Questionnaire</b>	<b>CAD patients</b>	<b>Population-based group</b>
The Uppsala Sleep Inventory, USI (II)	0.81	0.76
The Epworth Sleepiness Scale, ESS (II)	0.75	0.75
The Vicious Cycle of Sleeplessness Scale, VCS-8 (II)	0.90	0.89
The Hyperarousal Trait Scale, H-scale (II)	0.84	0.83
Medical outcomes study Short Form Health survey , SF-36 (II)	0.90	0.89
The Angina pectoris Quality of Life Questionnaire, APQLQ (II)	0.94	-
<b>CAD patients</b>		
	<b>Baseline</b>	<b>3-4 month follow-up</b>
The Epworth Sleepiness Scale ESS (IV)	0.78	0.81
Medical outcomes study Short Form Health survey , SF-36 (IV)	0.74	0.83

## Ethics

All studies were approved by the Regional Ethical Review Board at the Faculty of Health Sciences, University of Linköping. Principles according to the Helsinki declaration<sup>152</sup> were followed. None of the participants were in a dependent relationship to the investigator. Before participation, the participants were given written (I-IV) and verbal (I, III, IV) information about the study, the procedures and confidentiality and that withdrawal from the study would not affect their future care. When the recipients agreed to participate, they signed a written informed consent form. Informed and written consent was obtained from all participants in the studies II-IV.

The participants were given a code name in all studies. The code key was only available to the researchers (AJ, UE-G) and confidentiality was guaranteed. The participants were informed how to contact the study nurses and the researchers [AJ (I, IV), U E-G (II, III)] in case of questions.

In study I the participants were informed that the interviews were audio-recorded and verbally transcribed. There was always time in connection with the interview to take care of emotions, questions etc. that occurred during the interview. The individualized non-pharmacological programme in the



intervention study (**IV**) was not standard care at the hospital, no study participants were excluded from their normal care. No risks were identified for the participants and all interventions were evaluated to be beneficial for the participants and to promote health. Studies **II-IV** have been registered at Research and Development (FOU) in Sweden (Diary number 1833/3252).



# RESULTS

## Variations of self-perceived sleep

The CAD patients' perceptions of how sleep is influenced by rest, activity and health were identified in three descriptive categories (I); *My lifestyle is reflected in my sleep behaviour*, *Handling the practices around tiredness and sleep*, *Feeling of negative and positive efficacy*. The study showed that the patients' knowledge about sleep, attitudes and behaviour and the effect of these in a positive or negative aspect in their context, resulted in how they managed their sleep behaviour (Figure 9)

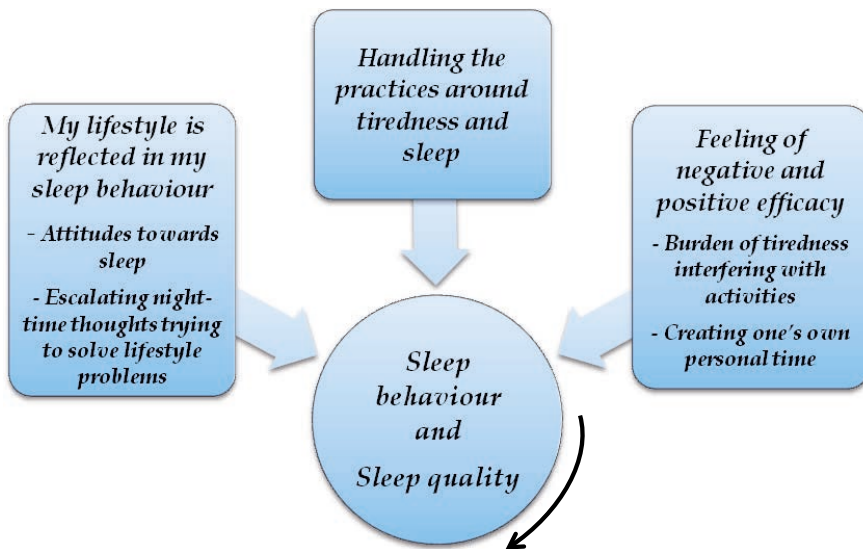


Figure 9. From a holistic perspective, the descriptive categories together are all of importance for promoting healthy sleep.

Two subcategories were revealed within the descriptive category *My lifestyle is reflected in my sleep behavior*; *Attitudes towards sleep* and *Escalating night-time thoughts trying to solve lifestyle problems*. Attitudes were based on experiences

and knowledge about sleep and sleeplessness behaviour. Three variations of sleep behaviour were identified. Patients who prioritized their sleep described experiences of a balance between sleep, rest, activity, vital health and good sleep quality. Patients who described that they did not have time for sleep counteracted sleepiness, e.g. with activities. There were also non-working patients who described a more neutral attitude toward their sleep problems. They described a sedentary lifestyle that permitted sleeping or resting during the day.

The patients described their thoughts, ruminations and internal dialogue just before bedtime and during nocturnal awakenings to be some of the major difficulties in falling asleep. These *escalating night-time thoughts* and dialogues were related to their health, activities, work and relations. In addition, they also thought about reactions after different events, perceived demands and future plans. Through this internal dialogue they tried to figure out how to adapt to a healthy lifestyle. They also tried to identify self-care behaviours to improve their situation. Some tried to manage the situation by reversing negative thoughts into positive ones, through relaxation or performing an activity or by just repressing their thoughts. On the other hand, some patients described their thoughts as not being followed by any actions. The internal and external demands were for some associated with distress due to them not being able to sleep. The internal dialogue escalated and reactions such as anxiety, worry and sadness were experienced, sometimes these emotions progressed and lead to increased sensitivity, fatigue/loss of energy and exhaustion.

*Handling the practices around tiredness and sleep* described the patients' use of intentional strategies to manage sleepiness and tiredness, whereas others were not aware of managing strategies. The patients described variations in tiredness, coupled with sleepiness when going to bed and falling asleep, or not being able to fall asleep. Experiencing tiredness was not enough to fall asleep, they had to wait for sleepiness. Patients described the utility of an intentional nap during the day, they felt more alert and rested after a short nap, but not too late in the day. Other patients denied that they took a nap but used other concepts to describe an intentional or unintentional nap as for example '*...nod off..., ...doze off... or ...gone for a while...*'. Nocturnal sleep loss, partly resulting from chest pain, was compensated by others through longer daytime naps. It was easier to relax and sleep during the day because of a feeling of being safe.

*Feeling of negative and positive efficacy.* Within this descriptive category the patients described that beliefs, motivation, attitudes and implemented changes influenced the effects of sleep loss. The subcategories that emerged were *the burden of tiredness interfering with activities* and *creating one's own personal time*. Mental tiredness was a burden in particular when great demands or a situation of insufficient knowledge or skills were perceived, such as demands from the family, work or health care. Several patients described a lower level of activities and that they were less vigorous, partly due to physical and mental tiredness and symptoms in combination with unpleasant feelings. Lack of knowledge on how to act or how to go about lifestyle changes and lack of psychological support led to feelings of uncertainty. Own personal time gave more energy, better recovery and made the patients feel more relaxed. Patients experienced that it was hard to create time of their own due to them being guided by others or perceiving feelings of fear and anxiety as a hindrance for being alone. The patients experienced that they had nobody to talk to about their needs for self-assumed activities, other patients denied signs and symptoms of the need to rest and they never prioritized themselves.

## Insomnia and non-rested insomniacs

Study II demonstrates that non-rested moderate or severe insomniac CAD patients have five to six hours nocturnal sleep duration and, on average, spend 23–38% of their time in bed awake (Table 4, p.2795, paper II). The severely non-rested insomniac patients' sleep duration was about two hours shorter/night than the population-based group. The short sleep duration was more likely compensated by significantly more daytime naps and less physical exercise (Table 9, p.55). In addition, CAD patients scored for statistically significantly higher daytime sleepiness (ESS) than the population-based groups (Table 9).

Men and women with CAD (II) scored significantly higher for non-rested moderate and non-rested severe insomnia than men and women from the population-based groups. In addition, the women with CAD scored statistically significantly higher for non-rested severe insomnia than the CAD men ( $p=0.0001$ , Figure 10).

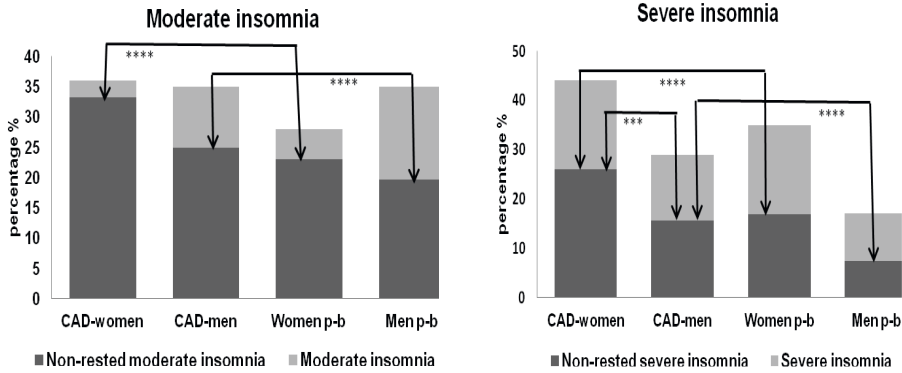


Figure 10. The proportions of non-rested moderate insomnia and non-rested severe insomnia (II). p-b = population-based group. \*\*\*p-value <0.001, \*\*\*\*p-value <0.0001 (p-values only presented in the frame).

## Sleep and general arousal

Study II showed that all groups with the exception of men from the population-based group had lower SE% than recommended for recovery (recommended value being  $\geq 85\%$ ). In addition, CAD women had statistically significantly lower SE% than both CAD men ( $p < 0.0001$ ) and women from the population based-group ( $p = 0.0001$ , Table 9). Women with CAD (II) also scored statistically significantly higher for sleeplessness and hyperarousal behaviours (VCS-8 [ $p < 0.0001$ ] and H-scale [ $p < 0.0001$ ]) than CAD men. In addition, compared to women in the population-based group, they also scored for greater problems with the exception of introspectiveness and extreme responses (Table 9).

CAD women had statistically significantly shorter sleep duration ( $p = 0.005$ ), more frequent wake bouts ( $p = 0.036$ ), higher fragmentation index (FI,  $p = 0.019$ ) and lower SE% ( $p = 0.046$ ) during one week of actigraphy registration compared to the matched women in the population-based sample (III, Table 10). None of the CAD patients had FI score for good sleep ( $< 20$ ). In addition, six of the CAD matched women ( $n = 13$ ) had FI  $> 50$ , which indicates disrupted sleep. Nine of 13 CAD women and 5 of 16 CAD men had  $< 6$  hours mean sleep duration during 1 week ( $p < 0.042$ ).

Table 9. Comparison of sleep efficiency, sleep quality, excessive daytime sleepiness, prevalence of daytime naps, general arousal, physical exercise and disease-specific quality of life within and between the patient and the population-based groups, respectively (II).

	Patient group		Population-based (p-b) group				P-value
	Women (W)	Men (M)	Women (Wp-b)	Men (Mp-b)	W vs Wp-b	M vs Mp-b	
	n=324	n=556	n=324	n=55			
Sleep Efficiency <sup>a</sup> (%)	Md (Q1-Q3)	Md (Q1-Q3)	Md (Q1-Q3)	Md (Q1-Q3)			
Sleep quality <sup>b</sup>	75 (64-87)	84 (72-93)***	82 (67-90)	89 (80-100)***	0.0001	<0.0001	
Nocturnal sleep duration (hr:min)	3 (2-4)	2 (1-3)***	2 (1-3)	2 (1-2)***	0.001	<0.0001	
A daytime nap score <sup>c</sup>	6:30 (5:30-7:30)	7:0 (6:0-7:30)	7:0 (6:0-7:30)	7:0 (6:20-8:0)**	0.081	<0.0001	
ESS <sup>d</sup> > 10 score (%)	3 (2-4)	3 (2-4)	4 (3-5)	4 (2-5)	<0.0001	<0.0001	
	27	33	19	22	<0.0001	<0.0001	
<b>General arousal</b>							
VCS-8 <sup>e</sup>	7 (3-13)	5 (2-10)***	5 (2-10)	3 (0-6)***	0.001	<0.0001	
HSUM <sup>f</sup>	33 (27-40)	29 (22-35)***	31 (25-39)	26 (22-34)***	0.002	0.003	
Introspectiveness	8 (6-11)	7 (5-9)***	7 (5-11)	6 (4-9)***	0.055	0.029	
Reactivity	4 (3-6)	3 (1-5)***	3 (1-5)	2 (1-3)***	<0.0001	<0.0001	
Extreme responses	3 (1-5)	1 (0-3)***	2 (1-4)	1 (0-3)***	0.20	0.767	
<b>Physical exercise<sup>g</sup></b>							
3a Vigorous activities	1 (1-1)	1 (1-1)**	2 (1-3)	2 (1-3)***	<0.0001	<0.0001	
3b Moderate activities	2 (1-2)	2 (2-2)***	3 (2-3)	3 (3-3)***	<0.0001	<0.0001	
3d Climbing several flights of stairs	2 (1-2)	2 (1-2)***	3 (2-3)	3 (2-3)***	<0.0001	<0.0001	
3g Walking more than 2 km	2 (1-2)	2 (1-2)	3 (2-3)	3 (2.5-3)***	<0.0001	<0.0001	
<b>Disease-specific quality of life (APQLQ)<sup>h</sup></b>							
Emotional distress	68 (56-80)	72 (56-88)**					
Somatic symptoms	57 (43-70)	60 (47-73)**					
Life satisfaction	56 (44-72)	60 (44-76)					
Physical activity	40 (27-57)	43 (27-60)*					

<sup>a</sup> the ratio of nocturnal sleep duration and time in bed in per cent (SE%). <sup>b</sup>A higher score indicates worsened sleep quality, perceived during the last four weeks, 1-5(well-badly). <sup>c</sup>A daytime nap scored 1=almost or every day, 2=3-5 days/week, 3=1-2 days/week, 4= < 1 day/week, 5=never or less than 1time/month. <sup>d</sup>The Epworth Sleepiness Scale. <sup>e</sup>VCS= Vicious Cycle of Sleeplessness Scale, measure sleeplessness behaviour. A higher score indicates a greater problem. <sup>f</sup>The total score on the Hyperarousal scale, measures hyperarousal behaviour. A higher score indicates a greater problem. <sup>g</sup>Items 3a-b, 3d and 3g from the SF-36 rated between (1) yes, very, (2) yes, little and (3) no, not at all limited. <sup>h</sup>The Angina Pectoris Quality of Life questionnaire. Range score 0-100, a higher score indicates better specific quality of life. \*\* p-value < 0.01, \*\*\* p-value < 0.001, \*\*\*\* p-value < 0.0001.

Table 10. Matched gender comparisons of sleep between coronary artery disease (CAD) patients and the population-based sample in study **III** assessed by the Uppsala Sleep Inventory (USI) the last 4 weeks, sleep diary for 1 week, actigraphy recordings for 1 week, daytime sleepiness by the Epworth Sleepiness scale (ESS).

	CAD-matched patients n= 29		Population-matched sample n= 29		P-value
	Women (W) n=13	Men (M) n=16	Women (Wp) n=13	Men (Mp) n=16	
	Md (Q <sub>1</sub> -Q <sub>3</sub> )	Md (Q <sub>1</sub> -Q <sub>3</sub> )	Md (Q <sub>1</sub> -Q <sub>3</sub> )	Md (Q <sub>1</sub> -Q <sub>3</sub> )	
<i>Sleep quality 1 (good) - 5 (bad)</i>					
USI	2 (2-3)	2 (2-3)	2 (1-3.5)	1 (1-2)	0.77
Sleep diary <sup>b</sup>	3 (1-3)	2 (2-3)	2 (2-3)	2 (1-3)	0.78
<i>Sleep efficiency (%)<sup>a</sup></i>					
USI	78.1 (73.7-89.6)	85.7 (76.6-93.3)	86.9 (68.6-91.8)	93.3 (67.0-99.2)	0.45
Sleep diary <sup>b</sup>	75.1 (61.0-88.2)	78.4 (72.0-91.2)	78.5 (67.3-82.8)	84.2 (67.8-92.8)	0.47
<i>Epworth Sleepiness Scale (n,%)</i>	3 (23.0)	10 (62.5)	2 (15.4)	5 (31.3)	1.00
<i>Actigraphy recordings</i>					
Sleep duration <sup>b</sup> (h)	5.2 (3.0-6.1)	6.1 (5.3-6.6)	6.3 (5.7-6.7)	6.1 (4.7-7.0)	0.005
Sleep efficiency <sup>a,b</sup> (%)	64 (32-76)	73(65-80)	72 (64-78)	74 (64-80)	0.046
Wake bouts <sup>b</sup> (freq)	23.6(19.9-29.1)	22.6 (19.9-27.5)	17.3(16.7-21.9)	23.1 (20.7-29.7)	0.036
Fragmentation index (FI) <sup>b,c</sup>	43.5(30.2-111.3)	36.7 (32.3-44.0)	36.3(24.2-43.3)	37.2 (30.6-51.7)	0.019
Total activity score <sup>b</sup>	11785 (6827-51663)	8582(6968-9981)	6690 (6379-11116)	9595(5244-13701)	0.011

<sup>a</sup>(SE%) = the ratio of nocturnal sleep duration and time in bed in percent, figures below 85% indicate insufficient sleep efficiency. <sup>b</sup>Mean value for 1 week. <sup>c</sup>FI indicates restless sleep; summary of percentage of minutes moving and percentage of immobility, bad sleep (> 50) and very good sleep (< 20). Complete table is shown in manuscript **III** (Table 4).



## Sleep quality and sleep efficiency

Sleep quality (II-IV) was measured by the question “*How have you slept the past 4 weeks*”(USI) and in the sleep diary (III, IV) “*How did you sleep last night?* ” The answers were assessed on a 5-grade scale, from good/well-badly, score 1-5, respectively. In study II, CAD women scored for worse sleep quality than both CAD men ( $p<0.0001$ ) and women from the population-based group ( $p=0.001$ , Table 9, p. 55).

In study II, the sum of scores for H-subscale (five questions from H-scale, Figure 11), VCS-8 and physical exercise (four questions from SF-36, Table 9, p. 55) were all correlated to a dichotomy variable for perceived sleep quality during the last four weeks in CAD patients (0= Well or rather well, 1=rather badly or badly, USI). Correlation was strongest to VCS-8 ( $r= 0.64$ , Figure 11).

The sum of scores for the variables mentioned above was also significantly correlated with SE% (Figure 11). After having been included in a multiple model for variance analysis and controlled for age, gender and known disease (hypertension, diabetes, MI and gastrointestinal problems) the three variables were still significant and could explain nearly 30% of SE% outcome ( $p< 0.001$ , Table 6 p.2797, paper II).

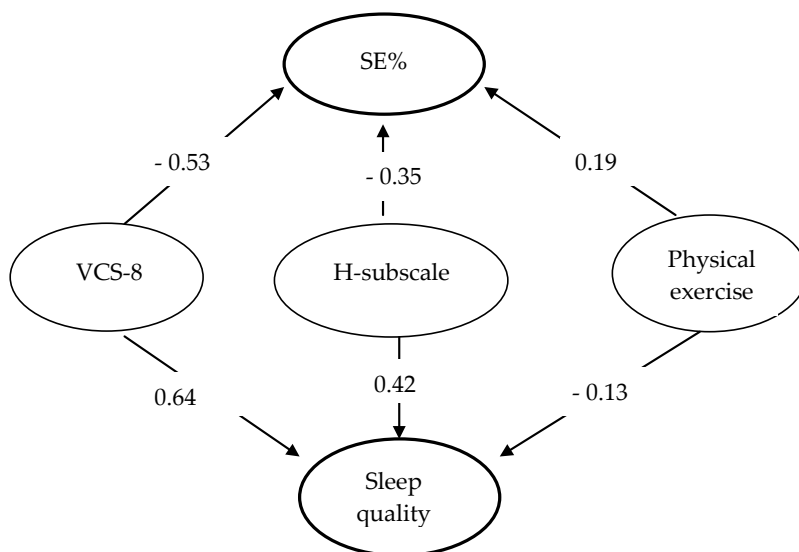


Figure 11. Sum of scores for the Vicious Cycle of Sleeplessness Scale (VCS-8), the Hyperarousal sub-scale (five questions<sup>a</sup>) and physical exercise (four questions in SF-36, Table

9, p. 55) were all correlated to sleep efficiency (SE%) and to a dichotomy variable for sleep quality (II). Spearman's correlation coefficients are based on pair-wise correlations. <sup>a</sup>From the Hyperarousal Scale; "I get rattled when a lot happens at once", "In bed at night, my thoughts keep going", "A sudden, loud noise would cause me a prolonged reaction", "Some thoughts return too often", "I keep thinking about the same things long after they happened". All correlations were statistically significant at the  $\leq 3$ - level (2-tailed).

A logistic regression analysis (II) showed that the independent variables VCS-8, H-subscale, and physical exercise accounted for 41% ( $p < 0.001$ ) of sleep quality outcome in patients with CAD, when controlled for age, gender and known disease (hypertension, diabetes, MI and gastrointestinal problems (Table 11), physical exercise was no longer statistically significant.

Table 11. Logistic regression analysis (II) of the relationship between the sums of scores for Vicious Cycle of Sleeplessness Scale (VCS-8), H-subscale<sup>a</sup> and physical exercise to predict sleep quality outcome in CAD patients ( $n=880$ ), when controlled for age, gender and known disease (hypertension, diabetes, MI and gastrointestinal problems).

Dependent variable	Independent variables	Beta	SE	p-value	Odds ratio	95% Confidence interval		ADJ <sup>d</sup> R <sup>2</sup>	p-value
						Lower Bound	Upper Bound		
Sleep quality <sup>b</sup>	VCS-8	0.31	0.03	0.000	1.4	1.3	1.5	0.41	<0.001
	H-subscale <sup>a</sup>	0.10	0.04	0.021	1.1	1.01	1.2		
	Physical exercise <sup>c</sup>	0.08	0.06	0.195	1.1	0.9	1.2		

<sup>a</sup>From the Hyperarousal Scale (five questions, Figure 11), <sup>b</sup>a dichotomy variable for perceived sleep quality (Uppsala Sleep Inventory, USI) during the last four weeks, <sup>c</sup>Physical exercise=Items 3a-b, 3d and 3g from the SF-36 (Table 9) scored (1) yes, very, (2) yes, little and (3) no, not at all limited. <sup>d</sup>Adjusted.

A multiple stepwise regression analysis in study III ( $n=104$ ) showed that self-reported sleep onset latency, nocturnal awakenings, sleep duration (USI), vitality (SF-36) and BMI accounted for 60% of the variance in sleep quality (USI) outcome ( $p < 0.0001$ , Model I, Table 12). In a second model, this study showed that SE% and FI together with sleep duration, all assessed by actigraphy, and sleep duration assessed by sleep diary, accounted for 36% of sleep quality (diary) outcome ( $p < 0.0001$ , Table 12).

Table 12. Multiple stepwise regression analysis of sleep quality scored on a 5-grade scale, from good/well [score 1] to bad [score 5], (n=104, **III**).

Dependent variable	Independent variables	Beta	SE	t values	p-value	95% confidence interval Lower Bound Upper Bound	ADJ <sup>a</sup> R <sup>2</sup>	F	p-value
I. Sleep quality <sup>a</sup>	Sleep duration <sup>a</sup>	-.343	.066	-4.875	<0.0001	-.452 -.190			
	Sleep onset latency <sup>a</sup>	.158	.002	2.309	0.023	.001 .009			
	Nocturnal awakening <sup>a</sup>	.365	.049	5.328	<0.0001	.165 .361			
	Vitality (SF-36)	-.338	.003	-4.916	<0.0001	-.022 -.009			
	BMI	-.174	.018	-2.621	0.010	-.081 -.011	.596	29.940	<0.0001
II. Sleep quality <sup>b</sup>	Sleep duration <sup>b</sup>	-.619	.091	-5.578	<0.0001	-.689 -.327			
	Sleep duration <sup>c</sup>	.710	.126	3.708	0.0003	.217 .718			
	Sleep efficiency <sup>c,d</sup>	-.588	.010	-3.295	0.001	-.053 -.013			
	Fragmentation inde <sup>c,e</sup>	.279	.004	2.062	0.042	.0003 .017	.363	15.555	<0.0001

<sup>a</sup>measured by Uppsala Sleep inventory (USI), perceived during the last 4 weeks. <sup>b</sup>measured by sleep diary, mean value for 1 week, <sup>c</sup> measured by actigraphy, mean value for 1 week, <sup>d</sup>(SE%)= the ratio of nocturnal sleep duration and time in bed in percent, figures below 85% indicate insufficient sleep efficiency, <sup>e</sup> Indicates restless sleep; summary of percentage in minutes moving and percentage of immobility, bad sleep (> 50) and very good sleep (< 20), <sup>f</sup>Adjusted, BMI= Body Mass Index.

## Effects of an individualized non-pharmacological intervention programme (IV)

At the 3-4-month follow-up, results of an individualized non-pharmacological programme to promote self-care in sleep-activity indicated that the intervention had improved sleep quality (USI, diary), sleep duration (diary) and SE% (USI, diary and actigraphy) among the patients in the I-group (Table 13).

At the evaluation of patients' goals in the I-group, it emerged that 18 patients (75%) had reported evaluated goals. Seven patients had achieved their goals (1-3 goals), 7 had achieved their goals in part and 4 did not achieve any of their goals. Examples of individualized goals.... *increase daily physical activity...no coffee too late in the evening...no naps or shorter naps...no napping too late in the afternoon...practicing relaxation ...calm down before bedtime (e.g. read for a while, solving a crossword)...go to bed later in the evening and only when sleepy...get out of bed when unable to sleep, not lay in bed awake for more than 30 minutes... keep regular hours regarding bedtime and get up time ...*

At 3-4 month follow-up 8 out of 24 patients (30%, missing values 5) in the I-group reported improved sleep in the sleep diary due to the CD-based relaxation programme (score  $\geq 2$  = to some extent to very much). The I-group also reported a statistically significant improvement regarding insomnia ( $p=0.02$ ) assessed by USI (Table 13).

A multiple stepwise regression analysis showed that sleep onset latency (USI: at follow-up), SE% (USI: at baseline) and sleep quality (diary: at follow-up) explained 51% of sleep quality outcome over the last four weeks assessed by USI at 3-4 month follow-up (Table 5, paper IV).

Table 13. Comparisons of sleep between the intervention group (I-group) and the control group (C-group) (IV) assessed by the Uppsala Sleep Inventory (USI) the last 4 weeks, sleep diary and actigraphy recordings for 10 consecutive days at baseline (M1) and at follow-up (M2) after 3-4 months.

	Baseline (M1)		Follow-up (M2)		P-value	
	Intervention group		Control group		I-group	
	n=24	n=23	n=24	n=23	M1 vs M2	M1 vs M2
	Md (Q1-Q3)	Md (Q1-Q3)	Md (Q1-Q3)	Md (Q1-Q3)		
<b>Uppsala Sleep Inventory (USI)</b>						
Sleep quality 1(good/well)-5(bad)	4 (3-4)	4 (3-4)	3 (2-3)	2 (2-3)	0.005	0.01
Sleep duration (hour:min)	6:0 (5:0-6:30)	6:0 (5:0-6:30)	6:30 (6:0-7:0)	6:0 (6:0-7:30)	0.10	0.05
Nocturnal awakening (freq)	3 (2-3)	3 (2-3)	1.5 (1-2)	3 (2-3) <sup>*</sup>	0.005	0.32
Sleep efficiency (%) <sup>a</sup>	65 (53-77)	68 (58-75)	79 (64-86)	78 (70-86)	0.008	0.004
Insomnia <sup>b</sup>	4 (3-4)	3 (3-4)	3 (3-4)	3 (3-3)	0.02	0.10
<b>Sleep Diary</b>						
Sleep quality <sup>c</sup> 1(good/well)-5(bad)	3 (2-3)	3 (2-3)	2 (2-2.5)	3 (2-3) <sup>*</sup>	0.009	0.97
Sleep duration (hour) <sup>c</sup>	6:0 (6:0-7:0)	7:0 (6:0-8:0)	7:0 (6:0-8:0)	7:0 (6:0-8:0)	0.04	0.21
Sleep latency <sup>c</sup> (min)	35 (21-62)	26 (13-38)	25 (16-34)	40 (16-58)	0.07	0.78
Sleep efficiency (%) <sup>a,c</sup>	73 (66-81)	83 (62-87)	83 (74-90)	84 (73-87)	0.005	0.33
Napping n (%)	17 (70.8)	17 (73.9)	10 (45) <sup>e</sup>	12 (57) <sup>e</sup>	0.04	0.02
<b>Actigraphy recordings</b>						
Sleep duration (hour:min) <sup>c</sup>	6:0 (5:30-6:0)	6:0 (6:0-7:0)	6:0 (6:0-7:0)	6:0 (6:0-6:30)	0.96	0.36
Sleep efficiency (%) <sup>a,c</sup>	71 (63-75)	73 (61-77)	74 (69-81)	72 (66-79)	0.004	0.36
Fragmentation index <sup>c,d</sup>	37.0 (26.6-47.1)	38.1 (33.7-48.2)	31.9 (26.7-48.6)	36.5 (30.7-50.0)	0.43	0.16

<sup>a</sup>(SE%) = the ratio of nocturnal sleep duration and time in bed in percent, figures below 85% indicate insufficient sleep efficiency. <sup>b</sup>Moderate insomnia = score  $\geq 3$  for difficulty falling asleep, maintaining sleep and early morning awakening and/or > 30 min sleep onset latency, > 30 min nocturnal awakening, early awakening > 30 min before desired morning awakening, and/or nocturnal sleep duration < 6 hr combined with at least one daytime symptom of sleep loss in the USI. Severe insomnia score  $\geq 4$  and/or combined with any of the above items. <sup>c</sup>Mean value for 10 days. <sup>d</sup>Fragmentation index indicates restless sleep; summary of percentage of minutes moving and percentage of immobility, bad sleep (>50) and very good sleep (<20). <sup>e</sup>2 missing values. \*p<0.05. Complete table is shown in manuscript IV (Table 3).

## Disease-specific quality of life and Health-Related Quality of Life related to insomnia

In comparison with CAD men, CAD women had significantly worse disease specific quality of life in three domains (II, Table 9, p. 55).

Figure 12 (II) visualizes gender differences in HRQoL for a matched population-based group vs. CAD patients (A), vs. patients with moderate insomnia (B), vs. those with previous MI suffering moderate insomnia (C) and those with diabetes suffering moderate insomnia (D), respectively. CAD patients estimated significantly worse HRQoL in all domains in the figures compared to the population-based group with the exception of CAD women with diabetes, where there were no differences in the domains social functioning (SF), role emotional (RE) and mental health (MH).

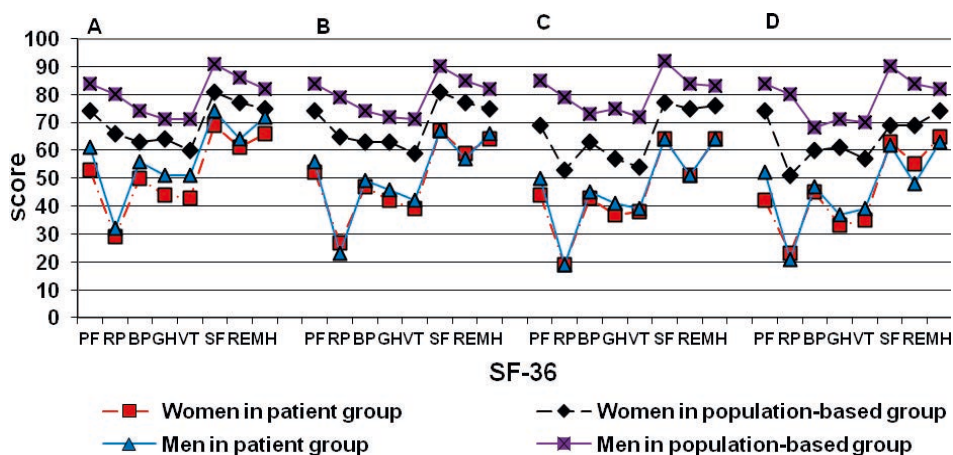


Figure 12. The figure includes four figures (A-D) i.e. gender differences in HRQOL for a matched population-based group vs. all patients (A); vs. patients with moderate insomnia (B); vs. those with previous myocardial infarction suffering moderate insomnia (C) and those with diabetes suffering moderate insomnia (D), respectively. The paired samples students' t-test showed statistical significance at < 3-levels between men in all compared domains in the SF-36 in Figures A, B, C and D as well as for women in Figures A and B. For C and D the statistical significance was at < 3-levels for PF, RP and GH, and at < 2-levels for BP, VT and MH in Figure C. In addition, VT in Figure D was at < 3-level.

PF=Physical function, RP= Role performance, BP=Bodily pain, GH= General health, VT= Vitality, SF= Social functioning, RE= Role emotional, MH= Mental health.

## GENERAL DISCUSSION

The overall aim of this thesis was to describe the impact of sleep quality and disrupted sleep on HRQoL in patients with stable CAD, compared to a population-based group. The objective was also to evaluate an individualized non-pharmacological programme to promote self-care in sleep.

In contrast to our hypothesis (II), the main finding shows only weak or non-significant gender differences with increasing insomnia severity in patients with CAD for sleep quality, SE% and general arousal regarding sleeplessness behavior (VCS-8) and hyperarousal behavior with impact on their disease specific quality of life. However, the above-mentioned variables had an adverse effect on both women and men with CAD.

An individualized non-pharmacological programme (IV) to promote self-care in sleep-activity could improve the patients' sleep quality, SE% and sleep duration, reduce nocturnal awakenings and daytime naps. The sleep variables were assessed by self-reported measurements (USI and sleep diary). In addition, SE% calculated by actigraphy recordings for 10 consecutive days was also improved.

Similar intervention studies have been performed to promote self-care management in cancer pain,<sup>153</sup> following CABG,<sup>154</sup> diabetes,<sup>155</sup> and heart failure,<sup>156</sup> and lifestyle changes in people with hypertension.<sup>157</sup> Our reflection is that self-care management interventions that enhance self-efficacy have been linked to improved outcomes. Little is known about the self-care behaviours that CAD patients perform in relation to sleep. It is of importance to identify barriers or strategies that CAD patients use to integrate sleep promotion actions or management of sleep problems into their existing repertoire of self-care strategies.

## Self-perceived sleep

### My lifestyle is reflected in my sleep behaviour

Patients' knowledge about sleep, attitudes and behaviour and the effect of these in a positive or negative aspect in their context, resulted in how they managed their sleep behaviour (I).

Those with positive attitudes towards sleep prioritized their sleep and described a balance between sleep, rest, activities and health resulting in positive effects on sleep quality. Some patients described that they did not have time for sleep, instead they tried to counteract sleepiness. A review study has described a link between negative perceptions with poor functional and psychological outcome in people with CHD.<sup>158</sup> Patients also described (I) a lifestyle with a more neutral attitude towards reported sleep problems. They had adopted a sedentary lifestyle and experienced nocturnal sleep loss as a minor problem according to their activities and self demands. This is in line with previous findings, where Ekman et al.<sup>159</sup> describe that patients with heart failure organize their life in a way that is compatible with their abilities and resources. The findings in the present study correspond with the relationship between sleep and health according to Pörn.<sup>19</sup> An individual's goal profile, repertoire and environment influence sleep and are thus important factors for good health.

Escalating thoughts, ruminations and internal dialogue just before bedtime and during nocturnal awakenings were described to be some of the major difficulties in falling asleep (I). Through this internal dialogue patients tried to figure out how to adopt a healthy lifestyle. These thoughts and dialogues were related to their health, work, relations and activities and also about reactions after different events, perceived demands and future plans. Sometimes the burdens of the day somehow returned at bedtime. Some tried to manage the situation by reversing negative thoughts into positive ones, through relaxation or performing an activity or just by repressing the thoughts. On the other hand, some patients (I) described their thoughts as not being followed by any actions. This partly corresponds with earlier research by Broström et al.<sup>160</sup> on heart failure patients. A reflection made is that if the patient is left to work things out by her/himself this may result in maladaptive beliefs about the disease and its symptoms i.e. that physical activities are dangerous. There is



some evidence that patients with chronic heart failure experience inability to trust their physical capacity and are thus prevented from attempting to perform activities.<sup>161</sup>

## Handling the practices around tiredness and sleep

Feelings of sleepiness, tiredness (mental or physical) and fatigue when going to bed were different presleep stages (I). Mental and/or physical tiredness and fatigue at bedtime were related to difficulties in falling asleep, whereas patients who felt sleepy, sometimes fell asleep quickly during a period of calming down. A sleepy individual does not only lack reaction to stimuli, but also falls asleep given the opportunity to do so.<sup>1</sup> It is important to consider the role of these presleep symptoms. Sleepiness is a basic physiological need state, similar to hunger and thirst. Sleepiness follows a normal circadian rhythm and is a result of the balance between sleep, rest and activity.<sup>162</sup> Prolonged accumulation of sleep deprivation without recovery sleep results in daytime sleepiness and decreased performance in both cognitive and physical functioning.

The patients used intentional self-care management strategies for promoting sleep quality such as cognitive behaviour self-help treatment, relaxation and distraction methods. The strategies and how to solve problems were associated with self-care behaviour and related to adaptation to daily life. This is also described in heart failure patients by Broström et al.<sup>160</sup> From a holistic perspective, the patients (I) that adapt to the situation or environment, experience good health if their goals have been attained.<sup>19</sup>

In the current study it was found that patients took an intentional nap to counteract daytime sleepiness, whereas daytime tiredness and fatigue more likely resulted in rest or reduced performance. It is described that excessive napping in older adults is related to decreased sleep quality and may be associated with negative health consequences such as increased risk of morbidity, CVD and cognitive impairment.<sup>163,164</sup> In contrast, another study did not support the relationship between napping and poor sleep.<sup>143</sup> A brief planned nap (max 20-30 minutes) may improve alertness, performance and health.<sup>163</sup> The nap-zone is partly considered to occur in the afternoon when the circasemidian biological activity rhythms are exceeded by sleep propensity time.<sup>29</sup> An important finding in the present study was that daytime naps and rest can be difficult to assess in a self-reported questionnaire. Several different concepts were used to describe a nap and rest. Many older adults may have

bouts of sleep during the evening but not report them as naps. This is also described by Ficca et al.<sup>163</sup>

An interesting finding in the present study was that some patients suppress sleepiness and the need for rest by an increase in activity and/or reductions in food intake to increase their alertness level. This behavior may increase the risk of CAD progression. A reflection is that using inconsequent self-care management strategies to promote sleep increases the risk of developing more negative cognitive thoughts and expectations about not having the control to change sleep. This state may aggravate the patient's sleeplessness behaviour and result in poor self-efficacy.

## Feeling of negative and positive efficacy

Feeling of negative and positive self-efficacy refers to the effects of sleep loss in association with tiredness and fatigue and the outcome of the implementation of one's own time.

Tiredness is a state of lack of energy and may be caused by mental or physical stress, symptoms related to the disease or medical treatment all resulting in poor sleep quality and increasing tiredness.<sup>49</sup> In the present study patients described mental tiredness as a burden when great demands or situations of insufficient knowledge or skills were perceived, such as demands from the family, work or health care. A tired or fatigued individual does not have the propensity to fall asleep given an opportunity to do so. Patients on peritoneal dialysis experiencing circling around in tiredness as an ongoing process extended over time linked to poor sleep that affected daily life by limiting activities, cognitive functioning and social activities.<sup>165</sup> These effects are also in line with findings by Broström et al.,<sup>160</sup> which in turn gave patients a feeling of not being in control of their own lives.

The patients (I) expressed that they experienced an unpleasant load of physical and mental demands ranging from tiredness to exhaustion. They lost their self-efficacy and thereby the capacity or the ability to continue performing desired activities which may result in a vicious circle of inactivity. This interfered with the patients' attempt to adapt to their lifestyle vision. There is some evidence that moderate physical exercise in the elderly may have a good recovery effect the following night, with a positive effect on sleep quality.<sup>87</sup> We believe that outdoor physical activity performed in daylight and environmental factors may improve sleep quality and counteract daytime

sleepiness. This may result in well-being and motivation to increased physical functioning.

The patients in this study (I) had a great need to create their own time, to carry out creative activities, rest and have time for reflection or just be. In turn this gave them more energy, they perceived well-being which promoted adaptation to a healthy lifestyle. It has been shown that cognitive and creative activities have positive effects on sleep quality.<sup>166</sup> The result suggests that ineffective strategies resulted in more introvert or a more safety-seeking behavior resulting in imbalance between sleep, rest and activity. We propose that in order to identify the patient's attitude to lifestyle changes, it is important to identify needs, feelings of motivation and interest, and risk behaviours in relation to self-efficacy. Having capability, capacity and skills to carry out various tasks gave an inner sense of strength that created motivation, interest<sup>167</sup> and enhanced self-efficacy.<sup>109</sup> According to Pörn<sup>19</sup> this influences the patient's behaviour and ability to adapt to their life situation.

## Self-reported sleep and actigraphy registration

The prevalence of moderate and severe insomniacs in women with CAD was 36% and 44% and for men with CAD, 35% and 30%, respectively (II). Research has shown that insomnia symptoms are associated with an increased risk for CAD<sup>168</sup> and acute myocardial infarction (AMI) compared with those who reported never or almost never having these insomnia symptoms.<sup>169</sup> In addition, gender differences have been evaluated showing that the association between insomnia and CHD was stronger in women<sup>170</sup> whereas the opposite was found by Mallon et al.<sup>168</sup>

In order to partly reduce confounding of symptoms related to underlying diseases and/or pharmacological treatment the proportion of non-rested insomnia was further analysed. It was found that 90% of moderate insomniac CAD women were classified as non-rested moderate insomniacs and out of these 59% were classified as severe non-rested insomniacs. For CAD-men the figures were 71% and 54%, respectively. This showed that NRS is one of the core symptoms of insomnia. This is consistent with previous studies<sup>65,171</sup> that suggest that NRS may exist even when insomnia patients do not report difficulty initiating or maintaining sleep. The burden of insomnia lies

essentially in the impact it produces on daytime functioning partly due to cognitive performance.<sup>172</sup>

Another important finding (II) showed that severe insomniac CAD patients displayed a two or threefold higher presleep arousal or anxiety score than the general population. The findings also showed that CAD women had statistically significantly more arousability than CAD men. In addition, the differences almost disappeared when associated with increased insomnia severity. Anxiety has been deemed to strengthen the association between insomnia complaints and risk of AMI.<sup>169</sup> Research indicated that an individual who suppresses their anger experiences elevated arousal, resulting in poor sleep quality and an increased risk for cardiovascular outcomes in patients with CHD.<sup>9</sup>

However, an important reflection is that all patients who are exposed to stressful events do not develop insomnia. Studies have found that predisposing factors are involved in the development of insomnia such as demographic (e.g. aging, gender), psychological (e.g. anxiety, depression), physiological (e.g. arousability) and lifestyle factors (e.g. smoking).<sup>57,173</sup> Stressful life events and/or psychological and health-related factors (precipitating factors) are usually associated with the onset of insomnia.<sup>40,57</sup> Nurses are ideal health care professionals to regularly assess sleep history and daytime functioning in order to identify symptoms and sleep problems. Assessment, decision-making and evaluation are needed continuously to help the patients their plan self-care management activities.

Morin et al.<sup>40</sup> reported a significant relationship between daytime stress and nighttime sleep in individuals with insomnia. Insomnia is perpetuated over time by psychological and behavioural factors, e.g. maladaptive sleep habits. It is known that presleep arousal and coping skills play an important mediating role.<sup>40</sup> A growing literature demonstrates that increased presleep cognitive activities such as ruminations, worry and anger suppression may contribute to poor sleep quality.<sup>9,174</sup> Furthermore, it is evident that stress and poor sleep quality per se lead to stress<sup>175</sup> resulting in elevated stress reactions and increased physiological changes.<sup>175,176</sup>

In a path analysis (II) it was found that physical exercise, presleep arousal or anxiety among CAD patients were all correlated to sleep quality and SE%. At the next step in a multiple model analysis and after control for age, gender and known disease (hypertension, diabetes, AMI and gastrointestinal problems) the variables were still significant and explained 30% for SE% outcome. For sleep quality a logistic regression analysis showed that the independent

variables mentioned above accounted for 41% in sleep quality outcome but when checked for age, gender and known disease, physical exercise was no longer significant. The findings from this study are consistent with Morin et al.<sup>40</sup> In contrast to our study, the participants in that study were from the general population, divided into good sleepers and participants with primary insomnia.

However, a reflection is that the relationship between stress and sleep may be independent of age, gender and disease. There may be patients that are more vulnerable and do not know how to manage their external and internal demands. CAD patients may have a propensity to ruminate after stressful events. Anxiety, intrusive thoughts and ruminations often related to the disease and significant losses are associated with higher levels of arousals at bedtime (presleep arousal state). It seems to be the perceived impact of the stressors that are of more importance than the number of stressful events. CAD patients who cope more adaptively with daily stress may go to bed more relaxed and sleep better. In an individualized non-pharmacological self-care management programme it is important to practice relaxation as this may be a way to calm down before bedtime, in order to create a relaxed state. Assessment of sleep and sleep behaviour in health care has to take the individual patient and context into account.

Sleep quality is a complex phenomenon that is difficult to define and measure objectively.<sup>177</sup> However, it is important to understand the subjective meaning of sleep quality.<sup>49</sup> Sleep quality is assessed by different issues. To assess sleep quality in studies a single question is often used,<sup>178</sup> as in studies **II-IV**. Other studies use an index i.e. the Pittsburgh Sleep Quality Index (PSQI).<sup>177</sup>

It was found (**III**) that sleep onset latency, nocturnal awakenings, sleep duration, vitality (SF-36) and BMI accounted for 60% of the variance in sleep quality (USI) outcome. Second, SE% and fragmentation index have a significant role together with sleep duration and accounted for 36% of sleep quality (diary) outcome. This study confirmed that group identity or gender did not emerge as being significant in the regression analyses. Our results are partly in consistency with studies in patients with peritoneal dialysis<sup>165</sup> and another study of CAD patients.<sup>10</sup>

The low levels of physical functioning, high BMI, poor sleep quality and stress that were revealed in study **III** can be connected with patients' lifestyle and predisposition to obesity. Review studies<sup>32,33</sup> have shown that short sleep duration is associated with impaired appetite control, glucose regulation and sympatho-vagal balance. We suggest that these pathways may play a key role

in the development of cardiometabolic disease risk. Sleep duration and sleep disturbances interact to increase the risk for CHD. This is particularly the case among those with restless or disturbed sleep.<sup>179</sup> Other studies<sup>180,181</sup> have shown evidence of a stronger association to women with detrimental cardiovascular effects.<sup>182</sup>

Generally CAD women scored lower for both self reported (USI, sleep diary) and objectively (actigraphy) measured SE% (**II**, **III**) than CAD men and women and men from the population-based groups. CAD patients with non-rested moderate or severe insomnia (**II**) had further reduced SE%. In addition, the population-based samples (**III**) had lower SE% than recommended for recovery. One may not only look at the value of SE% without examining what lies behind this value e.g. general health, arousal and physical functioning. SE% may have an impact on sleep quality.

Taken together with overall symptom cluster assessment it is important that health care professional documenting in patient records if the patient does not feel rested by sleep. Causes may be sleep apnea, daytime stress, pain conditions or restless legs. This may be of importance for the development of obesity, hypertension and cardiovascular disease.

Actigraphy showed low SE% for both women and men with CAD and in the population-based sample (**III**). The matched CAD women had statistically significantly shorter sleep duration, a higher frequency of wake bouts, a higher FI, total activity score and lower week-SE% compared to the population-matched women. All participants had lower SE% than recommended for recovery, CAD women had only 64%. We suggest that one reason may be that women go to bed earlier than men, i.e. they spent more wake time in bed. In the present study (**III**) there is a difference between subjective reported and objective measured SE%. It is, after all, bed time and get up time from the sleep diary that are used in actigraphy calculation of SE%.

The patients' attitudes towards sleep, knowledge about sleep and sleep behaviour can reflect whether patients have the capacity, capability and skills to perform self-care management activities and perceive self-efficacy in sleep and health per se. We hypothesize that making inconsequent decisions to improve sleep or not fully understanding the nurse's, physiotherapist's or physician's recommendations on how to improve sleep can be related to deteriorating cognitive functions. Partly, as effects of poor sleep quality over a longer period of time, which have been described in other studies<sup>49,183,184</sup> thus forming a vicious cycle.

## Individualized non-pharmacological programme

CAD is associated with specific self-care needs relative to exercise, diet, pain and medication management, among others. Self-care strategies used to promote sleep and manage sleep problems are important components of this complex regimen and may also improve functioning and HRQoL. Self-care management is a decision making process. To enable patients to make alternative self-care management plans, information and education about lifestyle changes and sleep hygiene can be helpful. Based on study **I**, **II** and **III** an intervention study was designed, aiming to evaluate an individualized non-pharmacological programme to promote self-care in sleep-activity (**IV**).

Study (**IV**) indicates that patients with CAD in the I-group who had undergone PCI, CABG and/or put on pharmacological treatment had statistically significantly improved SE%, both self-reported (USI, diary) and objectively (actigraphy) measured. They also had improved sleep quality, sleep duration, reduced nocturnal awakenings and napping assessed by self-reported measurements. The C-group, who also received a brochure about stress and sleep, showed only statistically significant improvements for sleep quality and SE% (USI) and reduced napping assessed by sleep diary. Both groups reported quite bad sleep quality at baseline, while the C-group had the greatest improvement at follow-up compared to the I-group. Compared to the study by Redeker et al.<sup>185</sup> on patients with stable heart failure and insomnia, the I-group in this study reported lower SE% at baseline and better SE% at follow-up. However, this was still lower than recommended, i.e. an SE% of at least 85%. Regarding sleep duration, the patients in this study reported shorter sleep duration at baseline compared to the overall sample (n=173) in the study by Redeker et al.<sup>185</sup> Furthermore, an interesting result (**IV**) was that the I-group had increased their median sleep duration assessed by sleep diary for 60 minutes at the 3-4 month follow-up (p=0.04).

In consistency with our study, another intervention study<sup>153</sup> based on a knowledge and attitude survey about cancer pain management, described education that was tailored to meet the patients' individual needs. The patients experienced changes in their perception of pain maybe as a result of the education, skills training and coaching by the nurses. The results suggest evidence for the benefit of developing individual care plans for each patient. Other research findings support the need for a gender-specific and

individualized targeted and tailored intervention to assist in symptom management and recovery from CABG.<sup>154,186</sup>

Evaluation of patients setting goals in the I-group (IV) resulted in 18 patients (75%) reporting evaluated goals. Seven patients had accomplished all setting goals (1-3 goals), seven partly and four did not carry out any of their goals. Our conclusion is that the majority of the patients followed the advice and tried to make a change to their situation, but a 3-4 month follow-up is too short for sufficient impact. The goal setting in the individualized non-pharmacological self-care management programme was intended to help the patients to actively participate in their own care, make informed choices about treatment and health care behaviours and engage in self-care with competence and self-efficacy. According to Pörn,<sup>19</sup> the patient and the nurse together (IV) set realistic individual goals according to the patient's own capabilities. Previous negative, unsuccessful attempts to change behaviour often result in a lower self-efficacy for future change in similar behaviour, and often lead to another failure.<sup>11</sup> A crucial step in changing negative experiences to positive is to set realistic goals. Goal settings combined with self-monitoring of the chosen behaviour, i.e. paying attention to the body, are the main tools to achieve a positive outcome. This in turn will increase self-efficacy for the chosen behavior.<sup>11</sup> In addition self-efficacy has been shown to be an important mediator for self-care and behaviour change. Improving patient self-efficacy may result in better health and lower costs to both the patient and the health care system.

Eight of 24 patients (30%) in the I-group reported improved sleep in the sleep diary due to the CD-based relaxation programme (score  $\geq 2$  = to some extent to very much) at the 3-4 month follow-up. Furthermore, despite individual recommendations by a physiotherapist regarding physical activities and relaxation training combined with a CD-based relaxation programme, the patients in the I-group had not increased their physical activity at follow-up. Surprisingly, the C-group experienced better physical functioning in the SF-36 compared to the I-group at follow-up. Our reflection is that the CAD patients experience unpleasant feelings, sense of uncontrollability and anxiety. They may be afraid of experiencing symptoms that are reminders of the cardiac event which may result in avoidance. It is known that CAD patients tend to drop out of treatment or fail to follow recommendations to reduce cardiac risk factors.<sup>187</sup> This may be a sign of anxiety or depression and therefore a cognitive behavioural individualized non-pharmacological self-care management programme which also focus on emotions, beliefs and attitudes have advantages. An approach to overcome the lack of knowledge and difficulties



with long-term adherence should include education on the benefits of physical activity and exercise training to both health care providers and CAD patients. It is also important to take into account that cognitive impairment may restrain the CAD patients' ability to make decisions and perform self-care actions. Knowledge and single education occasions alone do not always ensure improved self-care behaviour.<sup>188</sup> Nurse-led programmes with education and follow-up for patients with heart failure have been shown to improve self-care and fewer days spent in hospital.<sup>189</sup> These management programmes have also been proven cost saving and effective.<sup>190</sup>

The present study showed that even if patients' sleep was substantially improved in response to interventions by a minor education and training programme, the patients did not become good sleepers with values corresponding to those with good sleep. Similar restrictions have been reported by<sup>191</sup> following response to cognitive behaviour interventions in subjects with primary insomnia. However, The CAD patients' health needs to be considered in relation to what they can accomplish. Our findings support the idea that there is a need to better assess and take into account the patients values, attitudes and beliefs. With regard to this and by also considering the patient's physical and emotional abilities and beliefs regarding the impact the behaviour change will have on cardiovascular health, clinicians can develop individualized behavior change plans. Fostering self-determination and social support may be particularly helpful in promoting successful behaviour change.<sup>192</sup> Research indicates that more extensive interventions are needed to obtain improved self-care behaviours.<sup>188</sup>

Regular use of hypnotics was found to be associated with sleeping difficulties, depression and physical illnesses with an increased risk in all-cause mortality among men and women. Cause-specific mortality e.g. CAD death was most pronounced in men.<sup>193</sup> We suggest that nurse-led interventions based on a self-care management programme also provide an element of safety by giving patients knowledge of where to turn when their symptoms become worse. Therefore a non-pharmacological treatment for sleep problems may be preferred.

## Health, Quality of Life and Health-Related Quality of Life

According to Pörn,<sup>19</sup> total health care relates to the patient's context, not only to medical problems. Adapting to a healthy lifestyle depends on the patient's

understanding of good health, lifestyle and sleep pattern. The findings of the present study suggest that nurses had to take into account the additive effect of sleep variables (II) as well as focus on the CAD patients' individual perception of their sleep (I). In similar patient groups it has been shown that poor self-care may impair HRQoL and contribute to symptom burden and decreased functional capacity, but further research over time is needed.<sup>194</sup> There is a lack of knowledge about the management of these skills and it is therefore important for health care teams to support self-care management, and identify and set individual goals together with the patient in order to improve sleep and daytime functioning.

Epidemiological studies show that insomnia is associated with a decrease in HRQoL among patients with chronic illness.<sup>71</sup> Our study (II) confirms this finding. In addition, our study shows differences in HRQoL in the patient group compared to the population-based group. The differences in HRQoL between the male patients, with or without moderate insomnia, insomnia and MI or diabetes and the males in the population-based group were greater than the difference between the CAD-women and the women in the population-based group. Other research findings had also confirmed decreased HRQoL in patients with CAD compared to general population.<sup>195</sup> Assessment of HRQoL in clinic praxis is of importance in CAD, since the goal of intervention is not only to extend life but also relieve symptoms and improve functions and ability to participate in daily life activities.<sup>195</sup>

The patients in the I-group (IV) showed statistically significant improvements in role-physical, vitality and social functioning at the 3-4 month follow-up, no changes over time were revealed in physical functioning. One explanation could be that the patients were above average regarding physical activity and the sample was also very small. Another reason maybe that follow-up after 3-4 months is too soon. A recent study showed that PCI was associated with greater improvement in physical functioning up to 24 months after treatment compared to medical treatment alone.<sup>196</sup> Another explanation could be that several of the patients in the present study had undergone PCI before inclusion.

## Coronary artery disease and disease-specific quality of life

Based on a holistic approach, it is important to gain knowledge about the impact of angina pectoris on physical activities, symptoms, emotional state and life satisfaction, which affect quality of life. In study **II** a combination of the disease-specific instrument (APQLQ) and the generic instrument (SF-36) was used in order to capture the specific effects of the disease and its treatments on patients and enabling a description of a broad range of health states.<sup>21, 127</sup> Both disease-specific and generic instruments appear to be sensitive to HRQoL impairments.<sup>21</sup>

The results (**II**) show that CAD women experienced worse disease-specific quality of life than CAD men. This has not been described previously. Daily activities limited by chest pain, difficulty to relax, loss of energy and decreased mental state are conditions which have more influence on the CAD women's disease-specific quality of life. A disease-specific instrument may be useful clinically to evaluate symptoms e.g. after treatment and not only in relation to physical activity.

Research<sup>128</sup> has shown reduced mortality after invasive treatment compared to a non-invasive treatment in patients with stable CAD. In addition, to investigate the CAD patients self-reported disability APQLQ was used together with a generic instrument to evaluate HRQoL. The levels in the pretesting phase of physical activities, somatic symptoms, emotional distress and life satisfaction (APQLQ) corresponded fairly well with our results. Unfortunately, gender differences were not investigated.

## Methodological considerations

The strength of this thesis is that objective data from a total of 728 (**III**) and 940 (**IV**) sleep-wake cycles was collected by actigraphy recordings from CAD patients (**III**, **IV**) and a population-based sample (**III**). Self-reported data was measured by validated and reliability tested questionnaires. In addition a variation of qualitative and quantitative study designs were used.

Based on study **I**, **II** and **III** an intervention study (**IV**) was designed which aimed to evaluate an individualized non-pharmacological programme to promote self-care of sleep-activity (Figure 13).

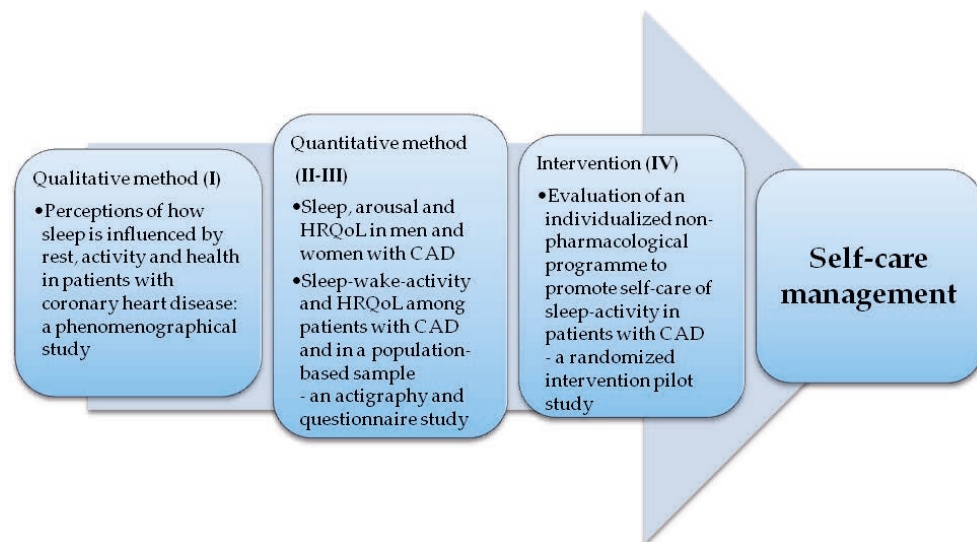


Figure 13. Based on a holistic perspective, this thesis used knowledge from studies **I-III** to develop the intervention study **IV**. This in turn highlighted the need for an individualized non-pharmacological self-care management programme to promote sleep.

## Samples

For study **I** a purposeful sampling was used to achieve variations in the data.<sup>117</sup> According to Marton and Booth<sup>117</sup> it depends on the variations among the individuals in the group studied whether the results are applicable to a larger population. Thirty-three patients from one university hospital and two general hospitals were interviewed. When deciding on the number of interviews, two aspects should be considered, the depth of the analysis and the aim to catch as many different conceptions as possible.<sup>119</sup> If there is too much data there is a risk that the analyses become superficial.

One strength is that study **II** is a multicenter study where 880 CAD patients were compared with an age- and gender matched population-based group which was randomly selected during the same period as the CAD patients. The response rate (**II**) was 70% among CAD patients and 60% for the population-based group, which was acceptable. To achieve an appropriate sample size (**II**) for a gender analysis with a 90% power and statistical significant level of alpha 0.01 and an effect size of 0.30/0.50, it would be

required to assess 233 CAD women and 331 CAD men for sleep quality. Study **II** included 324 women and 556 men. A limitation in study **IV** was that the patients were recruited from only one medical center. According to the calculated sample-size and power (**IV**), 50 patients were not retained in each group despite the long inclusion period. Internal dropouts occurred at a rate lower than 5% (**II**) and at a rate of 11% in study **IV**.

## Methods

A limitation in study (**I**) may be that three interviewers conducted the data collection. The audio taping of the interviews increased the credibility of the transcription process and the first author analysed the transcribed interviews.

Difficulties associated with the phenomenographic interview may be the respondent's motivation to participating. It may also be related to the researcher's understanding of what the respondent is trying to convey, to prevent misunderstanding the interviewer gave the respondents a short summary so that they were able to correct the information if necessary.

Questionnaires that have been validated and reliability tested were used. Internal reliability consistency for scales was calculated and showed acceptable values.<sup>137</sup> Combining a more comprehensive health profile, such as the SF-36, with a purely disease-specific instrument followed up with the health profile in a comprehensive manner secures its clinical relevance.<sup>21</sup> To compare treatments or in a rehabilitation period it may be a strength to use a generic measurement, such as SF-36. It is thus possible to compare scores between disease conditions and also with normative community reference values, in a standard manner. This may also be of importance in cost-effectiveness analyses.

Part of the study-specific sleep diary (**III**, **IV**) has been validated against polysomnography<sup>129</sup> and the Uppsala Sleep Inventory.<sup>129,142</sup> The design and questions were also adopted from and inspired by the literature.<sup>25</sup> A few changes were made in the sleep diary after study **III** to suit the purpose in study **IV**. Thereafter the design was tested on one patient through actigraphy recordings and by filling in the sleep diary for a consecutive 10-day period, respectively (**IV**). A standard self-monitoring sleep diary would increase the possibility for comparisons between studies and among groups in clinical practice. This has been recommended by an expert group in sleep research.<sup>197</sup>

Polysomnography (PSG) is considered the golden standard for measuring sleep objectively,<sup>198</sup> but due to the high cost and low availability it is usually

not performed for more than one night. Night-to-night variability in sleep-wake patterns is easily detected by using a sleep diary combined with an actigraph,<sup>198,199</sup> an objective validated<sup>130,149,150</sup> measurement. Actigraphy can with advantage be used for registration during longer periods in the home environment.<sup>130</sup> In study (III, IV) actigraphy was used which has several advantages. The actigraph can measure the circadian pattern of sleep and wakefulness over multiple sleep cycles and also show the presence or absence of increased wake time after sleep onset.<sup>200</sup> Actigraphy is an electrode-free, noninvasive and cost-effective method. The method is also much less expensive than polysomnography. Choosing ten consecutive days of actigraphy registration was important in order to be sure to include a weekend, when people can have a different rhythm in relation to other days of the week. However, one disadvantage may be that rest-activity patterns including indirect sleep measure periods of arm movements as wakefulness and inactivity as sleep. This may imply that actigraphy overestimates sleep latency and therefore should be used in combination with other diagnostic tools.

The individualized non-pharmacological intervention programme was performed according to the principles of self-care management in order to promote self-care of sleep-activity. An advantage with an individualized programme is that treatment can be tailored to the specific needs and capability of each individual.<sup>25</sup> Before the study (IV) the nurses and the physiotherapist underwent a 3-day education and sleep training programme. Sleep education elements, literature studies and clinical practice training were included. Knowledge about treatments of insomnia has been shown to be limited in the general population. There is a need for training programmes for health care providers. The intervention design was comparable to a clinical situation since the role of the nurse and physiotherapist were educational and supported the assumptions in cardiac secondary prevention care. The researcher was not involved with the education of patients in the individualized non-pharmacological programme. The patients were followed-up after 3-4 months which is quite a short period. Our suggestion is that a follow-up after one year is of importance. A reflection is that perhaps a more structured self-care management programme with continuous transmission of data, possibly every day through telehealth and more frequent follow-ups would result in better adherence and positive outcome in self-care management to promote sleep. Research has shown that combined individual-based approaches appear to be successful in creating behaviour change.<sup>13</sup>

A sleep brochure was given to both the I-group and the C-group which can make the significance of the intervention more evident. On the other hand, maybe the sleep brochure resulted in improvements in the C-group. The outcome variables were following sleep, sleeplessness behaviour and HRQoL parameters. No data regarding knowledge, self-efficacy and self-care management behaviour was obtained which can be a limitation.

## Analysis

In phenomenography the question is not how well the research outcomes correspond to the phenomenon as it exists in reality, but how well they correspond to the individual's experience of the phenomenon.<sup>201</sup> Another aspect of validity is that the phenomenographic approach indicates that the individual's experience of a phenomenon is context sensitive and can alter with changes in time and situation. When testing dependability the intersubject agreement was in the recommended range.<sup>119</sup> Furthermore, the first author discussed the preliminary categories together with the co-researcher and an agreement was reached. Finally, a phenomenographic researcher (MF) read the analyses in order to further specify the descriptive categories.

Several statistical analyses were performed and statistical methods were chosen and performed appropriately to the data i.e. sample size, between and within groups. The internal consistency (Cronbachs' alpha) of the questionnaires was recalculated and for some compared with the original testing. Cronbachs' alpha coefficient was acceptable for USI, VCS-8, H-scale, ESS and SF-36. In addition, the coefficient was fairly high in APQLQ (0.94) but corresponded to the original testing.<sup>126</sup> This may indicate that some of the questions were too similar. A limitation in this study (II) may be that standard diagnostic criteria were used to define insomnia but reported insomnia is not related to the prevalence of days/week. However, it was presumed that insomnia may fluctuate over a period of time i.e., during for example a 4-week period. The questionnaires used in this thesis take measurements over different time intervals. It is important to measure sleep over time. Insomnia complaints including daytime symptoms scored  $\leq 2$  measured by USI (II), was reported as mild insomnia but we do not regard it as insomnia. In our opinion, there may be an increased risk for developing insomnia, which may be prevented by general advice.

## Ethical reflections

The principles of the declaration of Helsinki were applied in all studies. Participating in the study required contribution from the participants, therefore it was very important that all participants were informed, both verbally and in writing about the procedure in the study and that withdrawal from the study would not affect their future care.

Burden for the patients were assessed continuously during the interviews (I) and was considered small.

In study II-IV several questionnaires were completed by the participants which might have been a burden for them. Furthermore, in study III and IV there was also a sleep diary to fill in, in the morning and the evening during 7 days and 10 consecutive days of actigraphy registration, respectively.

The intervention study (IV) called for greater efforts, therefore the research team always tried to be responsive to the patients' needs.

## Clinical implications

Identification, assessment, treatment and evaluation of disturbed sleep and tiredness belong to the health care professionals' responsibility. In the multidisciplinary team, the nurses have an important role in identifying patients with these problems and providing multifactorial risk reduction. It is important to identify symptoms and patients' perception of them. It is also important to take into account how the symptoms affect the patients in daily life. The CAD patients described feelings of sleepiness, tiredness (mental or physical) and fatigue as different presleep stages. Thoughts, ruminations and anxiety were related to difficulties to falling asleep, nocturnal awakenings and not feeling rested by sleep. To compensate for the sleep loss, a replacement nap was chosen and/or they had adapted to a sedentary lifestyle.

Symptom assessment and management of CAD patients should involve multiple symptoms. It has been found that symptom clusters may have more negative effects on HRQoL than symptoms that occur singularly.<sup>202</sup> Patients need to see the link between paying attention to their bodies (self-monitoring) and the improved self-care management that allows them to achieve more control over their lives. The patients have to be active participants in their treatment in order to have more ability to consider their needs and plan their self-care management.<sup>108</sup>



The patients described that self-care management strategies for promoting sleep quality were sometimes counterproductive. They had adapted to poor sleep habits with recovery consequences, and could not see alternative solutions. It cannot be assumed that patients can manage this situation on their own. To enable them to make alternative self-care management plans, knowledge and education about lifestyle changes and sleep hygiene can be helpful. Nurses must identify the patient's individual needs, and assess form management plans (short and long term) and evaluations in order to identify poor health habits. These must be considered from a holistic approach based on both qualitative and quantitative information. It is also important to identify the patient's attitude to lifestyle changes, feelings of motivation and interest and risk behaviours in relation to self-efficacy.

European guidelines on cardiovascular disease prevention in clinical practice recommend interventions adding psychosocial and psychoeducational components to standard cardiological care in order to improve QoL and diminish cardiovascular risk factors. However, there are no guidelines for sleep evaluation. In clinical practice, it is important to introduce guidelines including specific measurement for the assessment of sleep, psychophysiological status including stress, anxiety and sleeplessness behaviour to provide nursing care for both men and women with CAD.

This thesis supports the inclusion of questions on content selected areas such as sleep pattern over time, sleep quality and daytime effects in sleep history assessments, for example, "Do you get too little sleep", "How do you feel about the quality of your sleep, "How does your night's sleep affect your daily functioning and "Do you feel rested by sleep?" Questions about the circadian rhythm (the 24-hour clock) and physical activity are also of importance.

Nurses should focus on the patients and listen to them, establish a dialogue, provide information and support that can be effective in promoting sleep self-efficacy when planning patient care. A well-informed patient who knows who to turn to makes a secure patient. It is important that nurses with specialist expertise in cardiology are educated in leading individual non-pharmacological patient education.

Findings suggest that nurses' clinical assessment and interventions for patients with CAD should include a more comprehensive approach to symptoms including assessment of sleep and sleeplessness behaviour. Nurses engaged in cardiac rehabilitation and/or in supporting the management of heart disease may require further training in the application of cognitive behavioural techniques. Cognitive behavioural therapy for insomnia

is suggested to be effectively delivered by trained and supervised nurses in general practice.<sup>15</sup>

The results from the studies **I-III** were implemented in an individualized non-pharmacological programme (**IV**) to promote self-care in sleep-activity. The programme was based on six non-pharmacological components of management, thereafter a model was established (Figure 14). Implementation of an individualized non-pharmacological programme based on patients' needs to promote self-care in sleep-activity supported by a healthcare team and led by nurses is important in clinical practice and should be easy to use in daily clinical routines. To promote a positive health outcome it is essential to identify sleeplessness behaviour and perceived self-efficacy for self-care in sleep.

**Cognitive behavioural individualized non-pharmacological programme to promote self-care in sleep led by a nurse**  
- general prevention and early treatment to more specific individualized interventions

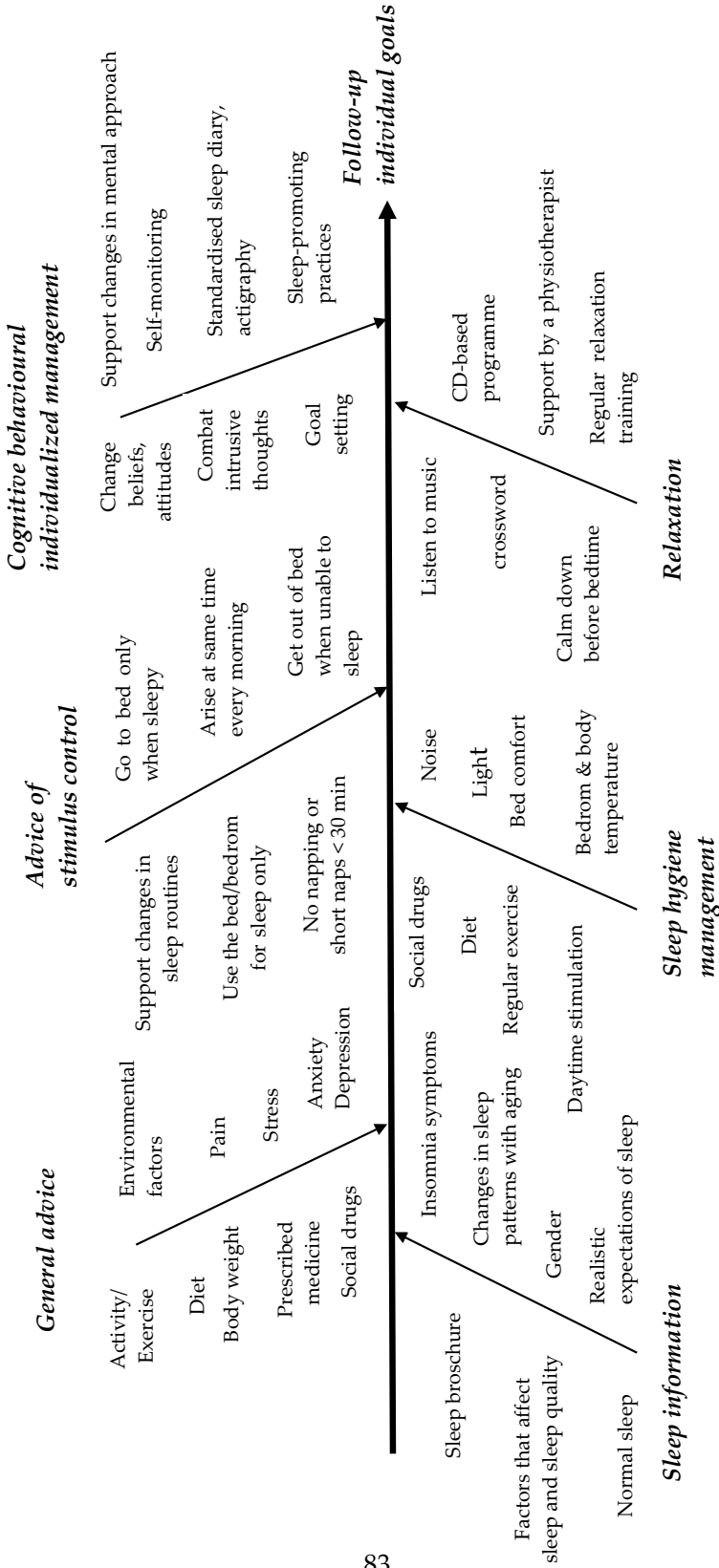


Figure 14. Stages of treatments range from general to more specialized interventions in an individual non-pharmacological programme related to the patients' context. This model was based on a holistic perspective and developed of knowledge from the studies I-IV. When a new components of area is introduce, earlier components are continued, several of these components of management are intended to run in parallel. The more specialized interventions requiring greater nursing skills.

## **Future directions**

Cardiovascular risk factors can be prevented or controlled by adherence to lifestyle recommendations. To promote self-care in sleep, evidence suggests that cognitive-behavioural strategies are an essential component of interventions targeting sleep behaviour.

In routine clinical practice and based on a holistic perspective, an individualized non-pharmacological programme to promote self-care in sleep may enhance self-efficacy, which in turn increases the chance of successfully adopting lifestyle changes. A self-care management programme should include self-monitoring and goal setting, realistic in terms of the individual's capability. It is evident that computer/internet-based transmitted strategies are effective in selected populations. This technology can certainly be further developed in self-care management. Furthermore, comparative studies with long-term follow-up strategies in routine clinical practice evaluating the effectiveness and efficacy of interventions are needed in order to identify which interventions are most successful in both initiation and maintenance. Multi-modal interventions may reduce periods of sick leave as well as health care costs. Evaluation of patients' sleep should be included in the European guidelines for cardiovascular disease prevention in clinical practice.

Furthermore, a longitudinal study to promote self-care in sleep-activity should be performed using a larger sample and multiple sites with continuous follow-ups to determine whether any positive effects remain stable over time. There is a need for nurse-based supportive care studies combined with a home communication intervention for reporting each day e.g. telehealth, tailored with more specific interventions that can be implemented by CAD patients to further maximize outcomes and establish guidelines for clinical practice.

## SUMMARY AND CONCLUSIONS

Based on the results achieved in this thesis the major findings are:

- Sleepiness, tiredness (mental or physical) and fatigue are different presleep stages.
- Patients used intentional and/or unintentional self-care management strategies, for promoting sleep quality, such as cognitive behaviour self-help treatment, relaxation and distraction methods for adaptation to daily life. Some self-care management strategies were counterproductive.
- The prevalence of moderate and severe insomniacs in women with CAD was 36% and 44% and for men with CAD, 35% and 30%, respectively.
- It was found that a large part of moderate insomniac CAD patients were classified as non-rested moderate insomniacs. This showed that NRS is one of the core symptoms of insomnia.
- Statistically significant gender differences in sleep quality, SE% and general arousal almost became absent with increased insomnia severity in CAD patients with insomnia.
- Short sleep duration was more likely compensated by more daytime naps and less physical exercise.
- Unexpected arousal behaviour and delayed poststress recovery after mental stress had a negative impact on the patients' sleep quality and SE% thus interfering with their HRQoL, independent of gender, age and co-morbidity.
- Generally low SE% was revealed in the studies, particularly among severe non-rested insomniac CAD patients.
- In order to identify factors that predict sleep quality, it was found that sleep onset latency, nocturnal awakenings, sleep duration, vitality and BMI accounted for 60% of the variance in sleep quality outcome.
- SE% and fragmented sleep (FI) assessed by actigraphy together with sleep duration measured by actigraphy and sleep diary, accounted for 36% of sleep quality outcome. The whole 24-hour period is of importance for assessing sleep-wake-activity. Actigraphy and sleep diary can with advantage be used over prolonged periods of time in the patients' homes or in a hospital environment.
- An individualized non-pharmacological programme to promote self-care management of sleep-activity including relaxation in patients with CAD supported by a nurse indicate to improve sleep quality.



## **SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH)**

Sömn är ett grundläggande behov, viktigt för fysisk och psykisk återhämtning. Insomni är ett samlingsnamn för sömnlöshet och relaterar till svårigheter att inleda och/eller upprätthålla sömnen eller ett förtidigt morgonuppvaknande. Detta i kombination med dagsymtom hos en individ som har tillräckliga förutsättningar och möjligheter till sömn. Förekomsten av rapporterade sömnstörningar varierar mellan 15-60% hos patienter med kranskärslssjukdom upp till 5 år efter kranskärslsoperation. Störd sömn kan ha en negativ inverkan på egenvårdskapacitet och beteenden. Lite uppmärksamhet har ägnats åt utvärdering av individuella icke-farmakologiska egenvårdsprogram för att främja sömn bland patienter med kranskärslssjukdom.

Avhandlingens övergripande syfte var att beskriva den påverkan sömnkvalitet och störd sömn har på hälsorelaterad livskvalitet hos patienter med stabil kranskärslssjukdom, jämfört med en grupp från populationen. Syftet var också att utvärdera ett individuellt icke-farmakologiskt program för att främja egenvård i sömn.

Fyra studier har genomförts under sju år, med början 2001. Patienter från sex sjukhus i södra Sverige inbjöds att delta i studierna. De jämfördes mot en populationsbaserad grupp från sydöstra Sverige som var ålder-, och kön matchad. Den matchade gruppen från populationen användes för jämförelser med patienter med kranskärslssjukdom i två av studierna. Data samlades in genom intervjuer, självrapporterade frågeformulär, studie specifik sömndagbok och actigrafi registrering. I interventionsstudien (pretest-posttest control design) utvärderades om effekten av ett individualiserat icke farmakologiskt program kan främja egenvård i sömn och aktivitet hos kranskärslssjuka patienter.

Resultatet visade en hög prevalens av insomni hos patienter med kranskärslssjukdom och en större del av patientgruppen uppgav att de inte var utvilade efter sömn. Detta visade att "icke-utvilad sömn" är ett betydelsefullt symptom på insomni. Resultatet visade att det var en svag eller icke statistisk signifikant könsskillnad med ökande svårighetsgrad av insomni. Kranskärslssjuka patienter med svår insomni visade en två-eller trefaldigt högre psykologisk eller fysiologisk stress och/eller ångest inför sömnen (presleep arousal) än populationsgruppen. De var också mer begränsade i

sin fysiska aktivitet. Sömneffektiviteten var generellt låg i alla studier, speciellt hos kranskärslsjuka patienter med svår icke-utvilad insomni. Det individualiserade icke-farmakologiska programmet för att främja egenvård av sömn-aktivitet indikerar på en förbättrad sömn och hälsorelaterad livskvalitet hos kranskärslsjuka patienter.

Denna avhandling visar att det är viktigt att fokusera på individens upplevelse av sin hälsa och sömn-aktivitet i patientens kontextuella sammanhang. Sjuksköterskor har en viktig uppgift i att stödja egenvårdsåtgärder och fastställa individuella mål tillsammans med patienten för att öka deras tilltro till sin egen förmåga för att främja hälsorelaterad livskvalitet.



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