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Patients' and Spouses' Perspectives on Coronary Heart Disease and its Treatment

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Linköping 2004

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*"I hear and I forget, I see and I
remember, I do and I understand."*

Confucius, 550-479 B.C.

To Terése

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Linköping 2004

Abstract

Background: Lifestyle changes and drug treatment can improve the prognosis and quality of life for patients with coronary heart disease (CHD), but their co-operation with suggested treatment is often limited. The aim of this thesis was to study how patients and their spouses conceive CHD and its treatment.

Material and Methods: The research design used was inductive and descriptive. The studies were based on three complementary sets of data. Patients with CHD (n=23) and spouses (n=25) were interviewed one year after an episode of the disease. Consecutive patients with CHD derived from another investigation were interviewed within six weeks or one year after the coronary event (n=113). All semi-structured interviews, tape-recorded or from notes taken by hand, were subjected to analysis within the phenomenographic framework.

Findings: The patients' conceptions of CHD varied and were vague, even as judged on a lay level. They were associated with symptoms rather than with the disease. Co-operation with drug treatment was rarely linked to improved prognosis. The patients' descriptions of benefits from lifestyle changes and treatment did not give the impression of being based on a solid understanding of the importance of such changes. Incentives for lifestyle changes were classified into four categories, all of which contained both facilitating and constraining incentives. Somatic incentives featured direct and indirect physical signals. Social/practical incentives involved shared concerns, changed conditions, and factors connected with external environment. Cognitive incentives were characterised by active decisions and appropriated knowledge, but also by passive compliance with limited insights, and by the creating of routines. Affective incentives comprised fear and reluctance related to lifestyle changes and disease and also lessened self-esteem. All incentives mostly functioned facilitatively. The cognitive and the social/practical incentives were the most prevalent.

Spouses' understanding about the causes of CHD involved both appropriate conceptions and misconceptions. Drug treatment was considered necessary for the heart, but harmful to other organs. Spouses' support to partners was categorised, and found to be contextually bound. The participative role was co-operative and empathetic. The regulative role controlled and demanded certain behaviours. The observational role was passive, compliant, and empathetic. The incapacitated role was empathetic, unable to support, and positive to changes. The dissociative role was negative to changes and reluctant to be involved in lifestyle changes.

Conclusions: These results could be useful in the planning of care and education for CHD patients. The findings also emphasise the importance of adopting a family perspective to meet the complex needs of these patients and their spouses in order to facilitate appropriate lifestyle changes.

Key words: Causal attributions, communication, coronary disease, drug treatment, lifestyle changes, phenomenography, patient adherence, risk factors, spouses, support.

ORIGINAL PAPERS

This thesis is based on five original papers, referred to in the text by their Roman numerals I-V.

- I Kärner A, Göransson A, Bergdahl B. (2003):
Patients' conceptions of coronary heart disease – a phenomenographic analysis.
Scandinavian Journal of Caring Sciences **17**, 43-50.

- II Kärner A, Göransson A, Bergdahl B. (2002):
Conceptions on treatment and lifestyle in patients with coronary heart disease – a phenomenographic analysis.
Patient Education and Counseling **47**, 137-143.

- III Kärner A, Abrandt Dahlgren M, Bergdahl B. (2004):
Coronary heart disease: causes and drug treatment - spouses' conceptions.
Journal of Clinical Nursing **13**, 167-176.

- IV Kärner A, Abrandt Dahlgren M, Bergdahl, B. (2004):
Rehabilitation after coronary heart disease: spouses' views of support.
Journal of Advanced Nursing **46**, 204-211.

- V Kärner A, Tingström P, Abrandt Dahlgren M, Bergdahl B. (2004):
Incentives for lifestyle changes in patients with coronary heart disease.
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List of abbreviations

AP	Angina Pectoris
BP	Blood Pressure
CABG	Coronary Artery Bypass Grafting
CHD	Coronary Heart Disease
CR	Cardiac Rehabilitation
HBM	Health Belief Model
MI	Myocardial Infarction
PBL	Problem Based Learning
PCI	Percutaneous Coronary Intervention
SRM	Self Regulative Model
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action

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INTRODUCTION

The problem of coronary heart disease at large

Coronary heart disease (CHD) is the main cause of death in Sweden and in most developed countries (1, 2). Evidence-based primary and secondary preventive efforts to reduce the risk of CHD have been launched in the USA and Europe (3, 4). Despite health promoting activities, the prevalence of obesity and smoking among CHD patients in Europe increased during a recent 4-year period. The proportion of patients with blood pressure above prescribed limits was similar, but those with high total cholesterol had decreased considerably (5). Results from the HELP study conducted in five European countries showed that among a general population only half regularly performed physical exercise, less than a fifth monitored their diet, and less than a third had made any health-related lifestyle changes during the last three years. This study also found that a high proportion of post myocardial infarction (MI) patients exercised only once a week, which is much less than prescribed. Patients in Germany and Italy had made significantly greater lifestyle changes and those in Sweden significantly fewer compared to other European countries. Despite these unfavourable results, the Swedish patients assessed themselves to be reasonably knowledgeable about CHD (6).

Thus, there is a discrepancy between what is known and what is implemented to attain the set goals. Regardless of primary and secondary preventive efforts, both the public and post-MI patients do not seem to act upon advice regarding positive lifestyle changes. There are also insufficiencies in health care in the treatment and follow-up of patients with CHD (7, 8).

There is a need to optimise and adjust health promoting messages and treatment to the individuals' needs. Consequently, it is a great challenge for all health professionals working in a variety of contexts to influence individuals to maintain health and reduce the risk of recurrence of CHD and the risk of death.

Starting point for the thesis

The studies this thesis is based on started in a clinical context on a medical ward and in an outpatient clinic caring for patients with CHD. In 1995, a discussion started about how to meet the CHD patients' needs regarding education and other types of support to increase co-operation with suggested treatment, and quality of life during the rehabilitation phase. The staff in the cardiac rehabilitation (CR) teams in Linköping and Norrköping started a project to

develop the traditional patient information input into a more extensive and self-directed learning model, with focus on the patients' knowledge and needs rather than instruction from the perspective of the staff. Inspired by the problem based learning (PBL) approach used in undergraduate programmes at the Faculty of Health Sciences, Linköping University, a patient education model based on these principles was developed. During this process questions were raised regarding what knowledge the CHD patients actually had about their disease and its treatment. The need to understand these issues was the starting point for the work in hand.

In order to problematise the issues studied in this thesis, a complex frame of reference was needed. This was constructed using knowledge from the fields of medicine, behavioural medicine, and nursing. This frame of reference was pragmatically used to understand and discuss findings in this thesis in a clear way. The researcher is a nurse with approximately 13 years' experience of working with CHD patients during various phases of their disease. An interest in public health issues is also present, documented by a Master of Public Health degree in 1997. This thesis should be read with this background in mind.

Coronary heart disease: Modifiable causes and treatment

There is increasing evidence that lifestyle changes and drug therapy affect the prognosis for and the wellbeing of patients with CHD (3). Traditional risk factors, which are independently and strongly related to the development of CHD, are hypercholesterolemia, hypertension, and smoking. Cigarette smoking is the single main avoidable cause of premature death and disability in industrial countries (9). Edwards claimed in a clinical review that giving up smoking has far higher protective effects in respect of death after MI than conventional standard treatments including trombolysis, aspirin, β -blockers, and statins (9). Survival and reinfarction rates were positively and significantly affected by cessation of smoking among post MI patients (10). Survival at follow-up 8 years after the MI was about 60% among those who continued to smoke and the corresponding figure for those who stopped smoking was 75%. Reinfarction rates at follow-up were 38% among the smokers and 22% among those who stopped.

The most important modifiable additional determinants of risk are obesity and physical inactivity (1). Psychological factors may play an aetiological role for CHD among healthy populations and also seem to affect individuals with CHD (11). A large body of evidence demonstrates that socio-economic status (SES) is importantly associated with CHD and has

consistently been shown to predict morbidity and mortality (12). Men in lower SES groups have also significantly more carotid arterial obstruction compared to cohorts including higher educated or wealthier individuals (13). The relationship between depression and the development of CHD is significant and independent of conventional risk factors. Studies have shown that depression is associated with two to three times higher mortality after MI, unstable angina pectoris (AP), or coronary artery by pass grafting (CABG), compared with such patients without depression (14). A recent meta-analysis of psycho-educational programmes indicates a reduction in cardiac mortality and new MI of 34% and 29%, respectively (15). However, results of such interventions have shown contradictory results (16, 17).

As drug therapy can reduce morbidity and mortality, co-operation with treatment is considered important (18). The first group of drugs found to improve prognosis was β -receptor blockers. A meta-analysis suggested that long-term β -blocking therapy reduced the relative risk of recurrent infarction (27%), and long-term effects on mortality (22%) (19). Aspirin has been shown to reduce vascular mortality (23%) nonfatal reinfarction (49%), and stroke (46%) (20). The Risk Group studied men with unstable AP and found that 75 mg aspirin/day significantly reduced the risk of MI and death compared with the placebo group at three months (21). The Scandinavian 4S study of the lipid-lowering drug simvastatin was the first to show positive effects of statins. Total mortality and cardiovascular mortality were reduced by 30% and 42%, respectively, in CHD patients (22). Furthermore, treatment with ramipiril (angiotensin converting enzyme inhibitor) significantly reduced rates of death, MI, and stroke in high-risk patients, who were not known to have low ejection fraction or heart failure (23).

Cardiac rehabilitation

The goals of CR are to promote secondary prevention and to improve quality of life (24). CHD has a multifactorial aetiology and, therefore, interventions with the aim of affecting morbidity and mortality must influence several factors in the patients' life situation. Comprehensive CR programmes have beneficial effects on several factors, i. e. mortality, exercise tolerance, functional capacity, lipid levels, blood pressure, symptoms of angina, weight loss, smoking, stress and psychosocial functioning, as reviewed by Grace et al. (25). According to a meta-analysis, cardiovascular mortality can be reduced by approximately 25 % in addition to the effects of other treatments, when patients participate in programmes (26). Winberg and Fridlund found that women benefited from participation in a CR programme in

relation to e.g. rehospitalisations. It was also found that the number of CABG/percutaneous coronary interventions (PCI) was almost double of that of the women in the non-CR programme group 4 years after their MI (27). However, research in this area indicates that attendance at CR is low, especially among women (28, 29).

Patient education is a key component of CR and serves important goals. These are e.g. to promote interactive communication between patients and healthcare staff; improve patients' and their families' understanding of the patients' health status; encourage patient and family participation in care, and promote a healthy lifestyle (30). For health education to be effective, it should be tailored to the patients' needs, which requires that health care staff understand patients' health and social characteristics and their beliefs, values, skills, and past behaviour (31).

Co-operation with treatment and lifestyle changes

A varying terminology has been used to describe patients' co-operation with drug treatment and lifestyle changes. Initially, the term 'compliance' was applied (32-34). Several definitions of this term have been used; one recent example is: "Compliance is a product not only of learning about the medical regimen, but also of the patient's lifestyle, a complex group of behaviours including social and family patterns, activities of daily living, and dietary, exercise and sleep patterns." (Rankin and Stallings, 2001, p. 10)(30).

Rankin and Stallings have criticised earlier approaches to compliance. They claimed that the term initially implied that health care professionals might dictate changes to the patients, who had to obey. Instead, they suggested that health care professionals should strive to enlist the patient's partnership rather than compliance and consider patient education as a process of influencing lifestyle in ways that are adequate to the patient (30). On the contrary, Sackett et al. argue that their use of the term does not carry implications of dominating physicians or submissive patients (35). Another expression, commonly used in more recent literature, is 'adherence' (36-38), which refers to a more active patient. The term non-adherence is also used and falls into two categories: unintentional and deliberate or intentional non-adherence (39). The former occurs when the patient's intention to take the medication is thwarted by constraints and disabilities, e.g. cognitive or physical problems such as poor understanding or reduced vision. The latter arises when the patient is reluctant to take the medication (39). It has also been pointed out that shared decision making between patient and physician is

important. For such a co-operation to take place, physicians must be able to explain medical information to the patient, and also be sensitive to his/her values and preferences (40).

In this thesis different terms will be applied. The concepts 'co-operation' or 'concordance' will mostly be preferred and used synonymously. These expressions have been increasingly applied in the literature (41, 42). They refer to an active and involved patient, whose resources and beliefs are looked for and considered with respect to the individual's decision about whether a concordant behaviour is aimed at or not (30). This implies that patients' decision about concordance with health promoting behaviour should be based on their newly acquired knowledge and reflections on possible factors that are believed to intervene with and affect the behaviour.

Despite the benefits of lifestyle changes and drug treatment, it is well known that a significant number of the patients do not co-operate with prescriptions to such an extent that therapeutic effects can be achieved (36). Studies carried out since the 1960s have dealt with this problem. Several investigations have estimated that up to 80% of patients who have been prescribed medication do not co-operate with instructions (36, 43-46). In addition, patients do not seem to accomplish changes in lifestyle. According to Dunbar- Jacob, it was estimated that between 13-76% of the cases of patients with CHD were co-operative in respect of diet change (36). Long-term participation in weight reducing programmes was estimated to be less than 50%, and fewer than that who maintained the weight loss, as reviewed by Burke. She also found that a higher proportion of hyperlipidemic women (59%) than men (45%) was rated as 'good' co-operators (47).

It has been pointed out that the rate of co-operation with physical exercise may be even lower compared to other medical regimens among chronic illnesses (48). The authors also discussed factors that contribute to the insufficiently co-operative behaviour. Three categories of factors were discerned, i.e. patient-related, regimen-related, and provider-related. A study was conducted among healthy middle-aged men with risk factors for CHD. They were randomised in subgroups: diet group (n=40), exercise group (n=39), and diet and exercise group (n=39). Despite verbal and written advice about diet and exercise, in which the former was also provided to their wives/partners, the results were unsatisfactory, especially regarding diet change. Only 20 vs. 29 % in the diet and the diet/exercise groups, respectively, displayed good concordance with advice about fat. Poor concordance with a low fat diet was linked with

smoking, younger age, and not having relatives or friends afflicted with CHD. Concordance with increased exercise was significantly higher in the exercise group than in the diet/exercise group (94.7 vs. 77.8% good concordance) (49). However, according to Dunbar-Jacob, who reviewed studies conducted over the 20 past years and more, found for example that patients adhered to exercise programmes of about 6 month's duration in about 50% of cases. In addition, the dropout rates were high and about 50% occurred within 6 to 12 months (36). She claimed that the figures were partially determined by the more demanding behavioural requirements, which were needed compared to drug taking (36).

Although, the prevalence of smokers has declined in Sweden, there is still a need to influence this generally health-threatening habit. Co-operation with smoking cessation has been suggested to be higher in more recent studies compared to earlier investigations, as reviewed by Burke. She reviewed papers in the past 20 years, which were randomised and focussed on populations at risk of CHD or those with established disease (47). Those assessed as earlier studies reported one-year quit rates of less than 50%, whereas more recently conducted studies reported rates of sustained cessation of 69% at six months and between 35% and 67% at twelve months. Positive effects of a smoking cessation programme, delivered by cardiac nurses without special training, significantly affected patients one year after admission to hospital care for CHD. Patients randomised to the intervention had a cessation rate of 57%, compared to 37% in the control group. The number of individuals it was needed to treat was five in order to get one additional person who would quit smoking. The authors claimed that a long intervention period is important in order to be able to affect the habit (50).

Non-co-operation with drug treatment has been reported to be a significant and greater problem than caregivers expect. For example, only 37% of patients with hyperlipidemia adhered to the medication to at least 90% or more (51). Non-concordance with anti hypertensive medication was reported by 47% of subjects attending a specialised clinic for hypertension (45). On the other hand, it has been found that the discontinuation rates reported in randomised trials may not reflect the actually observed rates in primary care settings (46). This study found that the one-year probability of discontinuation was between 15% to 45% for different lipid-lowering drugs (46).

Behavioural change

The problem that a number of patients display difficulties in achieving lifestyle goals has several causes. Lifestyle change is a complex process. Various psychosocial dimensions are important for recovery and readjustment after an event of CHD (52). A non-co-operative behaviour is partly affected by patients' conceptions and beliefs, which mostly occur in a context of social relationships (30, 48, 53, 54). Each of these components will be further discussed and explored.

Readjustment after chronic diseases comprises at least three psychosocial dimensions. The affective dimension refers to feelings and aspects, such as 'willingness to change'. The instrumental dimension is linked to actions and ability to perform a skill, while the cognitive dimension concerns basic facts and is accomplished when the patient can describe the illness in his/her own words (30, 52). Ben-Sira and Eliezer found that the cognitive dimension was the one most strongly associated with the management of demands to break habits among patients with CHD (52). A study within the phenomenographic framework further illustrates the importance of the cognitive dimension. This investigation by Svederberg concerned food choices and intake among three ethno-cultural groups of metalworkers and their families. Their choices were affected by conceptions of health, which were characterised as holistic, atomistic or fatalistic. The holistic view was characterised by subjective symptoms as well as objective parameters of the health situation; the atomistic attributed either symptoms or objective parameters and in addition distrust and scepticism about nutritional recommendations. The fatalistic view meant that neither subjective symptoms nor objective parameters regarding the present health situation were present. The ability to alter the health situation was not considered. Nutritional recommendations meant a decrease in choice and in the use of food with high symbolic value and an increase in the use of food with low symbolic value. This meant that no dietary changes were made. A low symbolic value of food was explained by earlier experience, such as sociocultural background (53).

Several theories for the prediction of behaviour have been developed during the last five decades (55-57). The health belief model (HBM) was launched in the USA by a group of social psychologists. Initially, HBM dealt with explanations about why people failed to participate in programmes to prevent and detect disease (57), and behaviours in response to diagnosed illness, mainly concordance with medical regimens (58). For behaviour change to succeed, individuals must, according to this model, feel threatened by their current behaviour,

which has been termed perceived susceptibility and severity. The model also involves that a certain change will result in a valued outcome at an acceptable cost of achieving behaviour change.

According to Montano, the theory of reasoned action (TRA) and the theory of planned behaviour (TPB) concern individual factors as determinants of the likelihood of performing a certain behaviour. The TRA includes measures of behavioural beliefs and social normative beliefs, which determine behavioural intentions (54). This is assumed to affect behaviour (55). TPB is an extension of the former theory and includes dealing with specific facilitators and constraints (56). These have been found to be important predictors of intention and behaviour. TPB has been used in explaining individual health behaviour including physical exercise, diet, smoking, stress (59, 60) and concordance with a medical regimen post MI, as reviewed by Fleury (61).

To sum up, the three dimensions, which are important for recovery and readjustment after a chronic illness, recur in the theories/models described above. For example, feelings of threat, perceived susceptibility, and severity, which are constructs within the HBM, concern affective and cognitive dimensions. This model also includes beliefs and appraisal that a change will result in an outcome at an acceptable cost, which involves the cognitive dimension. Another example is the TPB that concerns specific constraints and facilitators, which may be applicable to all three dimensions, i.e. cognitive, affective and instrumental.

Patients' and spouses' conceptions about disease and treatment

People have been found to vary with regard to how they conceive different phenomena in their surrounding world (62). Marton stated this line of reasoning, but without clearly linking conceptions to behaviours. In this thesis both conceptions and beliefs are considered to affect behaviour, but the former term is more linked to knowledge and understanding (62) and the latter to attitudes and behavioural intentions (55). However, these two concepts may be regarded as interchangeable. Beliefs may be understood as a kind of knowledge and conceptions may involve attitudes. Another term used in this thesis is experience, which, according to Marton, is comparable with conception (63).

Patients' and spouses' knowledge about CHD and its treatment has been studied both quantitatively and qualitatively. The former way has mostly been operationalized through

yes/no or true/false questions (64-66). The latter approach has dealt with explorations of experiences about phenomena, such as the disease itself, its causes, and the influence of cholesterol on the disease (67-69). Both methods are needed and serve different purposes in describing such knowledge. However, performing questions quantitatively reflects knowledge, which focuses on how much is learned rather than what is learned and may not reflect the patients' real knowledge (70). Assessing knowledge qualitatively is more likely to study active recall, i.e. the formulation of answers instead of mere passive recognition.

Wright et al. claimed that all individuals create explanations about important, unusual or unexpected life events. Conceptions about the cause/s of an illness are developed both by patient and family members (71). They also argued that the individual's conceptions about the illness contribute to the experience of the disease and thus forms the individual's feelings about the condition to a greater extent than the condition itself (71).

Conceptions of the causes of an illness may also colour the individual's knowledge about why the illness occurred. Such knowledge has also been viewed as crucial to prevention among spouses to patients with CHD (72). Petrie et al. argued that knowledge of the cause of an illness helps to make the illness less anxiety provoking and the future more foreseeable. They also claimed that the process of finding a cause or causes for e.g. MI helps patients to make sense of their episode of illness. It also provides a framework to guide future actions to deal with the illness (73). However, it is important to explore such conceptions, making it possible to reveal whether they facilitate or constrain the patient's way of handling the illness (71). In a recent study, patients afflicted with CHD mostly conceived that stress was the cause of the MI and when both patient and spouse were unable to find any obvious factors, fate was referred to (69). Findings from a quantitative study by Petrie and Weinman confirmed that post MI patients regarded stress, e.g. due to overwork, as the most important cause of their illness. Unhealthy lifestyles, such as inactivity, eating fatty foods, smoking, and being overweight were also commonly held as causes. This study also involved spouses and showed a high degree of concordance with patients about the relative importance of various causes. However, patients rated smoking and dietary issues significantly more important than spouses, who rated the patients' overwork higher than the patients did themselves (73). This study also examined the relationships between patients' beliefs about causes and changes in lifestyle six months after the MI. It was shown that patients who believed that an unhealthy lifestyle caused their MI significantly more often improved their diet and the frequency of

strenuous exercise. Beliefs related to stress or to heredity were unrelated to later changes in health behaviour (73).

Patients' knowledge about their CHD compared to established knowledge has been found to vary considerably. Qualitative studies on knowledge about cholesterol found satisfying results, as most patients could state their cholesterol level and label it as high-risk or borderline. They also knew that reduced cholesterol would decrease their risk for CHD (68). On the other hand, it was found that patients with a newly diagnosed CHD had difficulties in articulating causes of CHD and were not knowledgeable about their own risk factors (67). Spouses were found to underestimate the negative consequences of smoking. They conceived that its ability to act as a calming agent and relieve stress were more important than the negative effects on the body (69). Results from a quantitative study have shown that patients undergoing coronary angiography had less knowledge about general causes and personal risk of CHD compared to patients with MI. This study also suggested that individuals with risk factors for CHD are no more knowledgeable about causes for CHD than a sample taken from a general population (67).

One might question whether illness conceptions are stable over time. Petrie and Weinman assessed patients' conceptions about their MI on four occasions, shortly after the onset, and at 3, 6, and 12 months later. They found that patients' conceived control or amenability to cure of their MI decreased significantly over the year from onset. On the other hand, the patients' conceptions of how long the disease would last (time-line) showed a highly significant increase over the same period (73).

Investigations about patients' beliefs about drug treatment have also been performed. This type of research deals with an important question as to why some patients visit their doctors and then decide not take the treatment. Leventahl et al. developed the self-regulatory model (SRM), which suggests that health related behaviours or coping responses are heavily influenced by patients' own illness beliefs of the illness (74). Additionally, Leventahl argued that such beliefs are structured around the following five themes: identity (what is it?), timeline (how long will it last?), cause (what caused it?), consequences (how will it affect me?), and cure/control (can it be controlled or cured?). Consistent with the SRM, health-related decisions, e.g. to take medicine, are determined by beliefs about the nature of the

illness threat, which are followed by the patients' appraisal of the efficacy of their behaviour (39).

Horne and Weinman collected information from patients receiving regular medication for chronic illness, including CHD (39). The majority of patients believed that the medicine was necessary and effective, but one third of them were concerned about long-term effects and dependence. From a medical point of view, none of these drugs was regarded as liable to cause any dependence or addiction. Furthermore, patients living with Marfan syndrome conceived their medication as harmful, addictive, and unnatural (75), while hypertensive patients valued their treatment less than their doctors did (76). Horne and Weinman also found that patients who felt strong concerns about adverse effects of their medication, reported significantly lower co-operation with treatment than those conceiving it as necessary (77). Thus, most patients seem to have a complex view of medication. The necessity of medication was balanced against concerns about safety and disruptive effects of taking medication (39). These investigators claim that medication beliefs can be incorporated into Leventahl's SRM. The SRM terms coping and appraisal can be exemplified by their self-reported concordance with drug treatment (39).

Social support

Recovery from an episode of CHD occurs in a context of social relationships. The family is the individual's closest social environment and contributes significantly to patterns of behaviour and lifestyle (78, 79). Family members often share risk factors and may contribute to a co-operative attitude concerning risk factor modification of the patient (47, 80). The family also plays a major role for both sexes during recovery from CHD. Those unmarried or not socially integrated exhibited a greater risk of death, recurrence of CHD, and poorer psychosocial recovery compared to those married and/or socially well-integrated (81-84).

According to several investigators, the spouse has been considered to play an important role during the rehabilitation phase of CHD (85-87). It has been shown that post MI patients, who exhibited a high level of disclosure or who had communicative openness within their relationships, were less often re-hospitalised compared to those who did not disclose information to their spouses (88). Men with CHD rated themselves as dependent on their wives' actions (86). Support and encouragement from family members positively predicted wellbeing and the conception that life is meaningful despite the disease (89). Concerning

practical issues, spouse support was linked to self-esteem and mastery after MI (52). However, the need to modify certain aspects of the life situation can have a negative effect by starting conflicts, if the couple has different needs and priorities (79). In addition, a Finnish study revealed that the majority of spouses of patients with MI experienced a strenuous time during the recovery phase of their partners. The spouses displayed various kinds of stress symptoms, and had fears about the patients' leisure activities (90). Similarly, female spouses felt distressed during CR and used disengagement as a way to handling the situation significantly more often than those not distressed. Distressed patients also acknowledged significantly poorer family functioning and less intimacy (91).

A study of couples where one of the spouses was affected with CHD expressed that the main sources of information about cardiovascular risk factors were the media, friends, and neighbours, who most frequently referred to stress as the cause of the disease. Both patient and spouse considered fate to be responsible when no obvious risk factor was present (69). However, as reviewed by Burke et al., spouse support positively affected co-operation with lifestyle changes and drug treatment (30, 47). Therefore, not considering the spouse/family in patient education, may lead to poor recovery and inadequate co-operation with self-care (30).

AIMS

General aim

- to explore conceptions of CHD and its treatment during recovery from the illness from the perspectives of patients and spouses

Specific aims

- to broaden understanding about patients' conceptions of the nature of myocardial infarction and angina pectoris (Paper I)
- to investigate patients' conceptions, with focus on cognitive aspects of their drug treatment and lifestyle changes (Paper II)
- to explore spouses' conceptions concerning causes of CHD and drug treatment (Paper III)
- to investigate spouses' experiences of the rehabilitation phase of their partners' CHD, with particular focus on their views about support for lifestyle changes (Paper IV)
- to explore how men and women in the rehabilitation phase of CHD experienced constraining and facilitating factors related to lifestyle changes of importance for wellbeing and prognosis of the disease (Paper V)

MATERIAL AND METHODS

Patients and study design

The issues addressed in this thesis required the use of qualitative methods originating from the phenomenographic framework (papers I-V). An outline of papers in this thesis is shown in Table 1.

Table 1. Outline of papers in the thesis

Papers	Subjects	Data collection	Design	Data analysis
Paper I	Coronary heart disease patients n=23	Semi-structured interviews. Audio recordings 1 year after the coronary event	Inductive, descriptive	Phenomeno-graphical
Paper II	Coronary heart disease patients n=23	Semi-structured interviews. Audio recordings 1 year after the coronary event	Inductive, descriptive	Phenomeno-graphical
Paper III	Spouses to coronary heart disease partners n=25	Semi-structured interviews. Audio recordings 1 year after the partners event	Inductive, descriptive	Phenomeno-graphical
Paper IV	Spouses to coronary heart disease partners n=25	Semi-structured interviews. Audio recordings 1 year after the partners event	Inductive, descriptive	Contextual analysis
Paper V	Coronary heart disease patients n=113	Semi-structured interviews. Audio recordings n=10 and notes by hand n=103 within 6 weeks after the coronary event. From the 103 interviews 40 was collected about 1 year after the cardiac event	Inductive, descriptive	Inspired by phenomenographic framework

The inclusion of participants (papers I-IV) was determined according to strategic sampling design to achieve a variation in age, sex, profession, and residential area (92). Patients and spouses were approached with oral and written information about the studies. The interview guides were constructed by the research team and in contact with the CR staff. Before the data collection started, pilot interviews were carried out to test the research procedure, which led to some changes in the interview guide. The semi-structured interviews started with an open question on the topics included (Appendix I-II, page 69-70). Based on the answers, follow-up questions of metacognitive character, i.e. 'How do you think?' and 'Can you explain a little further?' were asked. The interviews lasted about 1½ hours. They were tape-recorded and later transcribed. The interviews were mostly conducted in the respondent's home or workplace, or at a hospital, according to their wishes.

Papers I and II

The following criteria were applied:

- CHD verified by MI, PCI or CABG
- coronary event about one year earlier
- Swedish speaking

Twenty-eight patients were considered eligible for this study. Of these, twenty-three patients were included. The mean age was 57 years old (range 53-61) for the men (n=14) and 51 (range 41-61) for the women (n=9). The interviewer encouraged the patients to express themselves in their own words during the interview. The intention was to explore the patients' understanding of the disease process, its treatment, and their views on the effects of lifestyle changes. The data were collected during 1995.

Papers III and IV

The following criteria were applied:

- living with a partner (< 70 years of age at the time of event) with CHD verified by MI, PCI or CABG about one year earlier
- Swedish speaking

Forty-nine spouses were considered eligible for the study. Of these 25 agreed to participate. The mean age was 52 year old (range 36-67) for the women (n=17) and 61 (range 46-68 years) for the men (n=8). There were two interviewers in this study; the author performed 12 interviews and a nurse in CR trained to interview conducted 13. The intention was to explore the spouses' understanding of the causes of CHD, their partners' drug treatment, and their views of the support given by them during the rehabilitation phase. The data were collected during the year 2000.

Paper V

The following criteria were applied:

- men and women with a recent episode of CHD verified by MI, PCI or CABG
- age <70 year old living in two cities in south-east Sweden, each of which had one hospital

Exclusion criteria were:

- planned intervention with CABG
- cardiac or other diseases with poor prognosis within one year
- disease affecting cognitive function, psychiatric or other mental disorders constraining communication or co-operation with others
- inability to communicate/read in Swedish
- obvious abuse of alcohol or narcotics
- participation in other studies assessed to affect processes or results

The data were derived from another study, which will hereafter be called the main study. It was an evaluation of PBL in patient education after CHD. The main study included 440 consecutive patients. Of these, 50 were excluded according to criteria described below. Of the remaining 390 patients, 207 decided to take part in the study and were included within six weeks after the episode of CHD. The research team developed a semi-structured interview guide and interviews were performed before randomisation, which started in January 1998 (T1) (see Appendix III, page 71). Follow-up interviews were performed one year later (T2) ending in October 2000. The interviews lasted 60-90 minutes and were conducted by two of the authors (A.K. and P.T.) and an educational psychologist. Before the data collection started, pilot interviews were carried out to test the research procedure. During the initial phase of data collection, the interviewers also compared answers from the patients as a way of

ensuring the quality of the interview performance. During this comparison the interviewers discussed how to explore the patients' answers by using probes. This also helped the interviewers to conduct the interviews in a similar way. The interview guide covered various parts to investigate and evaluate knowledge, attitudes, and intentional co-operation with treatment and lifestyle changes. The latter part regarding patients' intentions to change their behaviour concerns the present study.

A consecutive sub-sample of 113 participants from the main study was selected and included in the present study. Seventy-three consecutive patients, of which 33 were collected at T1 and 40 at T2, were called Group 1. The mean age of this group was 59.1 years ($SD \pm 7.1$ years). Group 2 comprised 40 consecutive patients at T1 and the corresponding figures were 57.3 years ($SD \pm 7.2$ years). The characteristics of the patients in the two groups are presented in Table 2. The present study dealt with five domains: physical exercise, diet, stress, smoking, and drug treatment with a focus on questions about the patients' experiences of facilitating and constraining factors. Examples are 'What are your possibilities to change your diet habits?' follow-up questions with the aim of exploring the initial answers were used; 'What makes it easier?' and 'What makes it more difficult/What hinders you?' The interviews were conducted at the hospital and lasted 60-90 minutes, including parts to be analysed later.

All interviews performed within this thesis aimed at establishing a trustful and open climate between interviewer and interviewee. The interview guides were semi-structured, which is the predominant method of collecting data within the phenomenographic framework (93). Although the guides were distinct in their structure, they were not compliantly adhered to. The questions expressed were adjusted to the actual domains and the sequence spontaneously chosen by the respondents. A conversational style was used during the interviews, with the guide as an aid to the interviewer, as described by Patton (94).

Table 2. Characteristics of the patients in % and (n)

Characteristics	Group 1 (n=73)	Group 2 (n=40)
Average age (SD)	59.1 (\pm 7.1)	57.3 (\pm 7.2)
Men	75% (55)	72% (29)
Women	25% (18)	28% (11)
Civil status		
Married	62% (85)	82% (33)
Living alone	12% (9)	13% (5)
Widowed	3% (2)	5% (2)
Education level:		
6-9 years' compulsory school	42% (31)	45% (18)
2-4 years' upper secondary school	47% (34)	45% (18)
University degree	11% (8)	10% (4)
No angina	67% (49)	58% (23)
Class I	24% (17)	40% (16)
Class II	7% (5)	0% (0)
Class III	1% (1)	2% (1)
Class IV	1% (1)	0% (0)

Secondary preventive activities

The patients referred to in this thesis took part in several secondary preventive activities. As an integrated part of care, members of the CR team informed the patients, in small group sessions and through written materials, about CHD and its treatment during the early rehabilitation phase of the disease. Family members/significant others were also invited. Areas covered were cardiovascular drugs, strategies for rehabilitation, health-promoting issues concerning diet, physical exercise, tobacco, and stress-related behaviours. The CR

programme consisted of physical training in a group and a session with a dietician. An appointment at a nurse-based outpatient clinic within one month after discharge was offered. Family members/significant others were also invited, if the patient approved. During this visit the above areas were reinforced and questions could be asked. The nurse could be reached by phone, if further questions occurred. Standard care also included one or two visits to a physician approximately 2-3 months after discharge. Patients with an uncomplicated course of illness were then referred to primary health care. The hospitals and primary health care had an agreed secondary preventive programme for these patients. The patients included in the main study were followed up at the hospitals during the year it was ongoing and then referred to primary health care. Twenty-one of the patients in paper V investigated at follow up after one year had also taken part in a patient education model built on PBL (95).

Research perspective

Phenomenography

Phenomenography is an approach that identifies, formulates, and deals mainly with research questions about learning and understanding in a pedagogical environment (70). This approach was developed in the early 1970s at the University of Gothenburg, Sweden. The analyses were initially performed to obtain a description of processes and outcomes of meaningful learning from the perspective of the learner (96).

A basic assumption in phenomenography is that people vary with regard to what meanings they ascribe to phenomena or situations in their surrounding world (62). The approach studies variations between qualitatively different ways of experiencing, understanding, and conceptualising phenomena. The kind of learning is focussed on and it is implied that learning has occurred when an individual is capable of experiencing a phenomenon in a new and qualitatively different way (70). Early results from phenomenographic research indicated the existence of a surface and a deep-level approach to learning, which were linked to an atomistic and a holistic direction of learning, respectively (70). Phenomenography was described as an empirical approach, but during the 1990s it developed towards a theoretical framework (97). Marton claimed that the approach was experiential, non-dualistic and an internal person-world relationship. The experiential ontology of conceptions means that there is no other world to humans than the experienced world. The internal-person-world relationship means that both subject and object constitute each other. The non-dualistic

characteristic implies that people cannot describe the world independently of their descriptions or of themselves as describers (63).

Phenomenography should, according to Marton and Booth, be regarded as a basic research approach with a certain origin and with an important usefulness in a certain context (70). This approach has moved outside its traditional educational context to be used by researchers in e.g. healthcare (93, 98-100). One important reason has been the need to describe basic conditions for patient education. For such activities to be effective, pedagogical skills are required (101). This means that health care staff need competence and understanding of how learning is accomplished to effectively facilitate learning among patients and significant others (30).

Marton's further work on the anatomy of awareness described that a person's way of experiencing something is related to how their awareness is structured. It involves both a *what* and a *how* aspect. The former aspect corresponds to the object itself, which implies that when people experience something, they are mostly oriented towards something discerned as central by them. The *how* aspect is related to the act and the structure of the experience described. It consists of the structural and referential (or meaning) aspects (97).

The structural aspect means that people do not only conceive different aspects or parts of isolated phenomena, but also organise and relate what is conceived to constitute a whole. The structural aspect is also built up by the external and internal horizons. The external horizon of a phenomenon can be described as the delimitation from a context to which it is related. The delimitation and the relating of parts make up the internal horizon of the phenomenon (70). The referential aspect, the meaning, which is closely linked to the structural aspect, constitutes the whole. When people discern the parts and the whole and their relationships, they also see the meaning of the experience (97). Svensson has developed this line of reasoning as contextual analysis (102). This research approach originates from the phenomenographic framework and shares its features in the analysis procedure on a general level. However, the former approach can be adopted in other types of data and for other purposes.

Contextual analysis is based on the fact that people's experiences of a phenomenon can be described by its components, their meaning, and their relationship with each other and to

whole qualities of the phenomenon (102). Svensson aimed at making delimitations and distinctions within the concept of study skill based on empirical data representing instances of study skill. He defined study skill as a relation between a criterion of learning and study activities related to a situation. This kind of analysis results in categorisations, relations between categorisations leading to portrayal of patterns of categories. A contextual analysis procedure comprises a cumulative comparison leading to a description of relationships between and within parts and whole qualities of the phenomenon studied (103). The analysis procedure implies a combination between explorative and interpreting features on the one hand, and analytical features on the other (104). The analytical element consists of discernment of parts considering *aspects* of the phenomenon under investigation. The discernment of *components* building up the aspects and their relationships is another analytical feature. The last explorative and interpretative step features the identification of the components' significance in the actual context (104).

The phenomenographic analysis procedure

The analyses in paper I-III have been performed according to the phenomenographic procedure and comprised the seven steps described by Dahlgren and Fallsberg (96). The procedure is illustrated by examples from the analysis in study III.

1. *Familiarisation*. The transcribed interviews were thoroughly read by the researcher, aiming at becoming acquainted with the content of the text in detail. This step was important for making corrections, as someone other than the researcher had typed the transcripts.
2. *Condensation*. Significant statements in the answers were selected to give a short description of what the interviewee brought into the discussion. In this step, it was important that the researcher ensured that the condensation really focused on what the interviewee had discerned as important. By addressing questions to the text, such as 'What is this spouse trying to say regarding the drugs prescribed to his/her partner?' Statements that were repeated and viewed similarly were selected.
3. *Comparison*. The selected significant statements were compared to find sources of variation or agreement. Several questions were addressed by the researcher to the text, e.g. 'What is considered as central to the spouse concerning drug treatment?' This question

helped the researcher to identify the *what-* aspect, which is a central concept in phenomenography. Moreover, questions such as ‘Why and how is this conceived as important by the spouse?’ were put to facilitate the identification of the *how-*aspect. Addressing these questions to the material helped the researcher to see more clearly how the spouses conceived the drug treatment prescribed to their partners. The process of comparing statements between the spouses was facilitated by the question: ‘Is this spouse’s statement similar or different from statements expressed by other spouses?’

4. *Grouping*. Similar statements identified in the former phase were grouped and preliminary categories were evolving.
5. *Articulating*. This step involved an attempt to describe the essence of the statements in each preliminary category. A process that involved questioning for and against the previous interpretations during step 2-4 was performed. Steps 4-5 were revised several times before the analysis was considered satisfactory. The aim was to establish categories, which were distinctly separated from each other.
6. *Labelling*. Each category was assigned a suitable expression, which captured the essence of the understanding. The labelling did not necessarily adopt the linguistic expressions stated by the spouses. Instead, abstractions based on the researchers’ judgements could be applicable.
7. *Contrasting*. The obtained categories were compared with regard to level of understanding on a meta-level. Comparisons between the categories led to a hierarchically ordered outcome space. This was established by performing a comparison of the categories and other studies that investigated the phenomenon in question. The categories were labelled A, B, C, starting from the best understanding in comparisons with established knowledge in the field. Less elaborated conceptions were assigned to the categories B or C depending on the understanding exhibited. To increase the credibility of the analysis, a co-examiner read citations to test the hierarchical categorisation. A process called ‘negotiating consensus’ followed, in which the suggestions put forward by the researchers were discussed in several rounds to reach an agreement about the final placement (105).

Description of contextual analyses procedure

The analyses in paper IV have been inspired by the procedure described by Abrandt Dahlgren (106). Three phases of analysis in relation to findings obtained are presented in Figure 1.

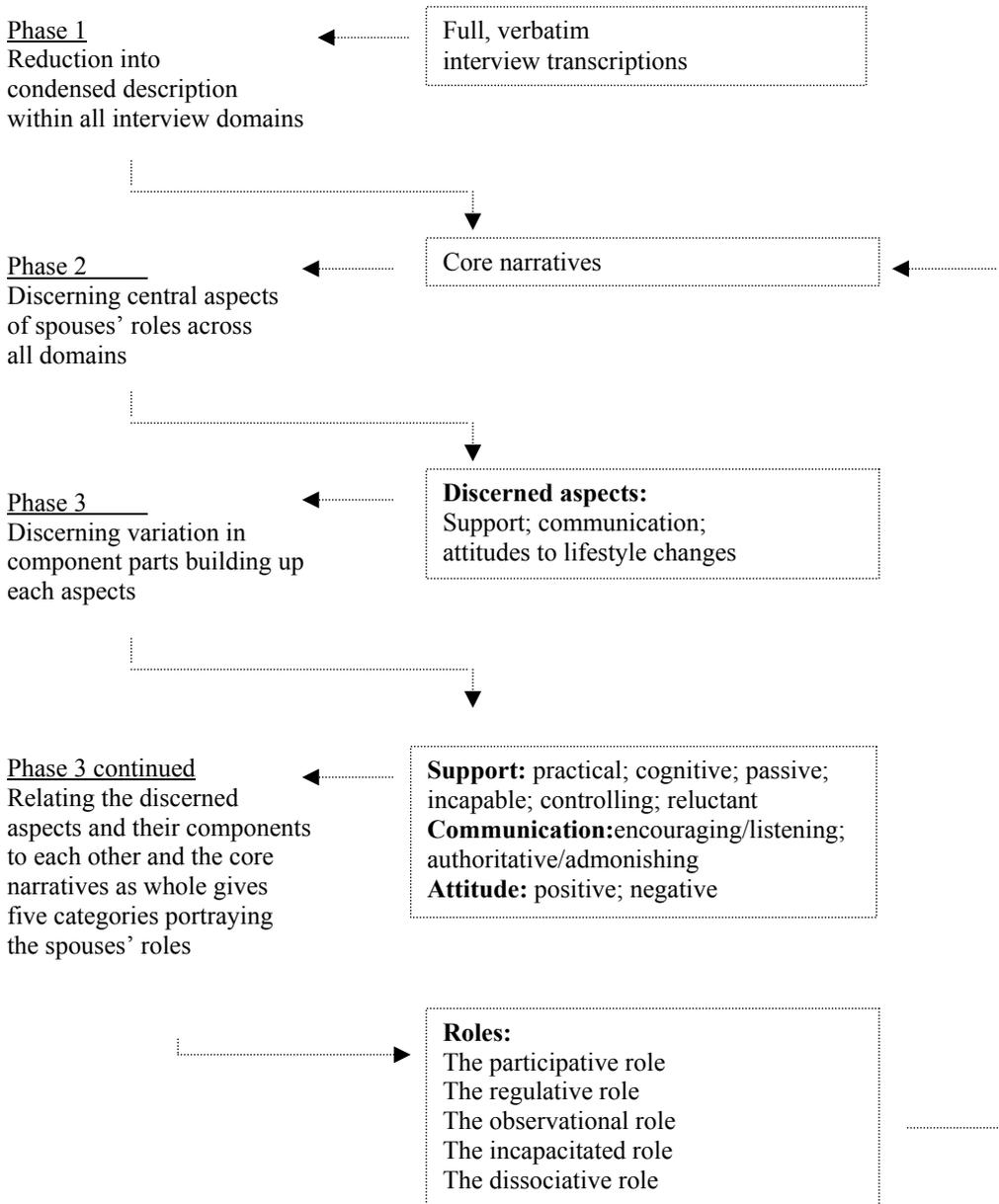


Figure 1. Phases of analysis in relation to findings obtained.

Phase 1. Data reduction

The transcriptions were read on several occasions to become acquainted in detail with the content. The full account in the transcriptions, which referred to the spouses' views concerning issues related to support after the CHD event, were reduced to 'core narratives'. This was performed within all interview domains: physical exercise, diet, stress, and smoking. All follow-up questions from the interviewer were omitted to allow the narrative to appear.

Phase 2. Delimiting aspects

The analysis continued by repeated thorough readings of the core narratives. The aim was to grasp their meaning as whole entities. The readings were performed with a question in mind 'What is this all about?' The preliminary results of the readings, which featured the *analytical* part of the analysis, yielded the aspects found in all four domains.

Phase 3. Identifying components

This phase has similarities with steps 3-6 in the phenomenographic analysis procedure. The *analytical* part of analysis proceeded. This resulted in the identification of components that build up the aspects delimited in the former phase. By analysing the internal relations between aspects and components and the core narratives as whole entities, a system of categories portraying the spouses' roles was identified. The internal relations between the aspects and the components were used to compare the categories in terms of similarities and differences.

The *explorative* and *interpretative* part meant that a search for the components' significance in the actual context was performed. The categories were exemplified by a condensed transcription of one core narrative characteristic of each category.

A procedure to increase credibility of the results was performed. A co-examiner read excerpts relating to all interview domains to test the categorisation of the material according to the identified components and categories. The process called 'negotiating consensus' followed, in which the categorisations and interpretations were discussed in several rounds to reach agreement about their final status (105).

Data analysis of paper V

Group 1 (see Table 2) involved 73 consecutive interviews and included 10 consecutive interviews at T1, which were taped and transcribed verbatim. Another 20 consecutive interviews at T1 and 43 at T2, documented by hand, were analysed to add to the development of the categories. All analysis was conducted with the inspiration of the phenomenographic framework, as described above (62, 96). After step 3 in the procedure, the analysis proceeded on a more abstract level, leaving the domains (physical exercise, diet, stress, smoking, and drug treatment) and focussing on features common to all domains. These features were identified as sub-categories and, more specifically, facilitating and constraining factors within the main categories were defined. Each main category was then labelled, and involved both negative and positive instances, as conceived by the patients to affect the behaviour. The process of 'negotiating consensus' was practised in this study as well (105). Finally, a delimited sub-sample of 40 patients, documented by hand and comprising the remainder of the participants at T1 at one of the hospitals, was used to investigate the distribution of incentives in the system of categories.

Ethical considerations

All studies yielding papers I-V were approved by the Ethics committee for human research at the Faculty of Health Sciences, Linköping University, Sweden. Informed consent was obtained from all participants before participation. They were informed that participation was voluntary, could be terminated at any time, and that confidentiality was guaranteed. For study V, a participant register was established according to directions from the Data Inspection Board (DIFS 1995:4), in a decision from the chancellor's office, Linköping University.

FINDINGS AND COMMENTS

The findings in papers I and II will be described from the perspective of the patients, and, where appropriate, briefly commented upon from the researchers' perspective.

Paper I

The aim of this study was to broaden understanding about patients' conceptions of the nature of MI and AP.

The nature of CHD

The analysis of answers yielded from the questions 'What is a heart attack?' and 'What is angina pectoris?' each provided three different categories.

MI was expressed by/as:

- A.** Involvement of blood and vessels
- B.** Involvement of either blood and vessels
- C.** Developed from AP or referred to risk factors/symptoms

AP was expressed or referred to as:

- A.** Insufficient heart capacity or involvement of vessel, blood, and oxygen
- B.** Atherosclerosis, or as contraction of a vessel
- C.** Symptoms

The categories labelled A represent an understanding that was assumed to involve reflection and appraisal regarding CHD. Several important components of the disease process, such as negative changes in the blood consistency and in the vessel wall were involved in the patients' descriptions. However, no patient referred to CHD by expressing it as a longstanding process starting before the acute cardiac event. The categories regarded as B included vaguer expressions compared to the former categories. Difficulties to elaborate reasoning on the issue were displayed. In the final categories risk factors/symptoms were expressed without linking them to the process of MI or AP. Several misconceptions regarding MI and AP were also found. It was believed, e.g. that MI was caused by a thrombus, which burst and tore the heart muscle apart. Another misconception regarded AP. It was expressed that the heart muscle lacked the strength to force the blood through the contracted blood vessels. AP was also

considered similar to cramp without mentioning the most important cause, i.e. atherosclerosis.

Paper II

The aim was to investigate patients' conceptions with a focus on cognitive aspects of their drug treatment and lifestyle changes. Focus was on cognitive aspects of four drugs known to affect the development and progress of CHD. Lifestyle changes regarded three domains, i.e. fat, physical activity, and smoking.

Drug treatment

Analyses of answers regarding a question about drug treatment 'How does it work?' resulted in two to four categories depending on the drug referred to. The categories differed substantially and although several patients mentioned important features of the treatment none clearly expressed that CHD prognosis was affected positively.

Aspirin

- A.** Prevents thrombosis, lifelong treatment
- B.** Prevents thrombosis
- C.** Thins blood
- D.** Refers to the chemical substance

Categories A and B conceived aspirin would prevent thrombus formation and the former involved an aspect of a timeline. Category C referred to effects on the blood consistency, but misconceived the effect of aspirin. Category D was not able to articulate any understanding of its effects.

Beta-blocking drugs

- A.** Counteracts symptoms of heart disease
- B.** Referred to the value of the treatment
- C.** Referred to a commercial name

Category A conceived beta-blocking drugs to relieve symptoms of different cardiovascular diseases, such as angina pectoris, arrhythmia, and hypertension. Category B viewed the drug as beneficial for MI in an unspecified way. Category C could not develop any

explorative answers to the question.

Lipid-lowering drugs

- A. Reduce blood cholesterol
- B. Referred to as a commercial name of the drug

Category A conceived the lipid-lowering drugs to decrease cholesterol. Few commented upon positive effects on the dangerous LDL cholesterol and the beneficial HDL cholesterol. It was expressed that ending the treatment was a possible way of finding out about its effect.

Category B could not elaborate on reasoning about the drug.

Angiotensin-converting enzyme inhibitors

- A. Cardiovascular effects
- B. Promotes respiration
- C. Referred to the heart in an unspecified way

Category A conceived the drug to reduce blood pressure (BP), promote heart capacity or dilate vessels. Category B referred to positive effects on constrained breathing, but did not link the symptom to CHD or cardiac failure, and category C conceived the drug to affect the heart in a general way. In this final category it was conceived that the drug controlled 'heart troubles'.

Co-operation with drug treatment

Another question regarded the patient's conceptions regarding co-operation with drug treatment. The answers regarding 'What happens if you don't take the drug properly?' provided three different categories:

Improper co-operation

- A. Risk of relapse
- B. Sense of insecurity
- C. Harmless because of lack of symptoms

The patients in category A conceived that drugs taken in an inappropriate way could affect recurrence and symptoms related to CHD. Category B referred to psychological needs by

referring to worries of getting signals from the body, indicating somatic illness. Category C did not conceive improper concordance with treatment as important, if it was not subjectively confirmed by somatic symptoms.

Risk factors for CHD

The question ‘Is it possible to avoid CHD?’ offered two different categories:

- A.** Partly avoidable through a healthy lifestyle
- B.** Not avoidable

The patients were able to express several traditional risk factors associated with CHD, e.g. smoking, heredity, fat intake and physical inactivity. Other factors mentioned were stress, anxiety, alcohol and having a cold. Category A referred to the fact that health promoting activities had preventive effects, and category B conceived that e.g. faith played an important role, implying it impossible to affect.

Fat intake

Two questions were put ‘Why is it important to eat less fat?’ and ‘Are there different kinds of fat? If so, which fats are preferable?’ The answers provided four and two categories, respectively. Findings from answers regarding the former question are presented first.

Effects of fat intake

- A.** Fat is detrimental to blood circulation, affects blood lipids, and body weight
- B.** Fat affects blood lipids and body weight
- C.** Fat is essential and increases body weight
- D.** Unable to describe any results

Patients in category A conceived that fat affects atherosclerosis, cholesterol levels in the blood, and body weight. Category B displayed a similar understanding, but without referring to the effects on the vessels. In category C, fat intake was considered useful. To stop using fat was expressed as having a negative effect. Patients in the last category explained lack of understanding of how CHD was affected by fat. Findings from answers regarding preferable fat are:

Preferable type of fat

- A. Animal fat should be avoided and vegetable/fish fat preferred
- B. Polyunsaturated fat should be avoided in favour of butter and olive oil

Reasoning regarding healthy fat qualities was found in category A. Some distinguished fish fat to be of better quality compared to pork. Refrigerated fat that remained soft was preferred to fats that became hard. However, less healthy choices were preferred in statements from category B.

Physical activity

This domain provided answers to the question ‘How does physical activity affect you?’ Three different categories were found. The two first categories display the same level of understanding.

Effects of physical activity

- A1. Medical effects of physical activity
- A2. Psychological effects of physical activity
- B. Mixed (positive and negative) feelings of physical activity

Physical activity was conceived to affect blood cholesterol and insulin dosage positively by patients with diabetes in category A1. The second category referred to positive emotional feelings related to physical activity. It was expressed that such activity diverted thoughts, and helped the patient to understand how much he/she could accomplish physically. The last category involved an ambivalent reasoning regarding this domain. Statements reflecting difficulties in altering old habits and finding motivation for such lifestyle change were found.

Smoking

The answers from the last domain considered the question ‘Why is smoking a risk factor for MI?’ and resulted in three different categories:

- A. Smoking negatively affects blood vessels, lung capacity, and oxygen supply
- B. Smoking reduces fitness and affects the lungs
- C. Smoking promotes health

The patients' understanding about this risk factor regarded unfavourable effects on different functions and organs in the body, as expressed in category A. The patients were able to relate this knowledge to CHD. In category B similar effects were mentioned without linking it to CHD. In category C, smoking was conceived to affect health positively. A misconception that smokers lived longer compared to non-smokers due to increased resistance was found.

Paper III

The aim was to explore spouses' conceptions concerning causes of CHD and drug treatment. Twenty-five spouses living with a partner who had had an episode of CHD were interviewed. Possible causes of CHD were explored by the question 'What causes CHD?' The spouses attributed the disease to various aetiological factors. Examples are unhealthy diet, stress, smoking, and physical exercise. These domains were further scrutinised by the question 'What does (the domain) mean for the development of CHD?' Follow-up questions were also used when required. Findings about physical exercise, fat intake, and stress are each presented in two categories; and those regarding smoking and drug treatment in three each. An overview of the findings is presented in Table 3.

Table 3. Overview of categories concerning coronary heart disease (CHD) and drug treatment.

Know- ledge	Conceptions concerning Causes of CHD				Conceptions of
	Physical exercise	Fat intake	Stress	Smoking	Drug treatment
A	Inactivity accelerates the CHD process	Fat hinders blood circulation in coronary vessels and leads to an MI	Stress strains blood circulation, causes vessel wall obstruction and MI	Smoking contributes to atherosclerosis thrombus formation and MI	Drugs prevent atherosclerosis, clot formation, MI, and the need of by-pass operation
B	Physical exercise increases risk for an MI	Fat affects blood viscosity	Stress is generally negative but especially for patients with MI	Smoking negatively affects physical fitness, blood vessels, lungs and the working of the heart	Drugs are necessary for the heart but harmful for other organs
C				Smoking negatively affects vessels	Constant drug intake damages functions and leads to disease

All spouses regarded physical exercise as positive during the rehabilitation of CHD. Conceptions about negative consequences of inactivity (category A) and also about rigorous exercise were revealed. Some spouses conceived the latter activity as a risk for relapse of CHD (category B), which was the most commonly held conception in this material. They expressed that the increased blood pressure during exercise would affect a thrombus to cause an MI. Fatty foods were commonly considered as a cause of CHD.

A change to healthy diet was viewed as an important preventive step. Understanding of different types of fat was mentioned. Some fats were conceived as having characteristics such as dangerous, hard, soft, of vegetable origin etc, while other spouses regarded fat in general to negatively affect CHD. Understanding of fat as constraining blood circulation in coronary vessels due to involvement in the atherosclerotic process, which may cause an MI, was found (category A). Some spouses conceived fat to affect blood viscosity (category B), but lacked understanding of its effects on vessels. Most conceptions were classified as category A.

About half of the spouses, mostly women, regarded stress as a cause of CHD. Stress was conceived to affect blood circulation and vessel walls, leading to an MI (category A), while some focussed on general issues of stress (category B). The spouses' conceptions were mostly considered as category B.

All spouses regarded smoking as negative for the body. About half of the informants viewed it as a cause of CHD. Two of the spouses were smokers, fourteen had stopped, and nine had never smoked. Some spouses considered smoking to contribute to atherosclerosis, thrombus formation, and MI. However, most of the spouses mentioned negative effects of smoking on physical fitness, and heart function and blood vessels (category B and C).

All spouses had opinions about their partners' drug treatment. Drugs were conceived to prevent atherosclerosis, clot formation, MI, and reduce the need for revascularisation (category A). Drugs were also considered as necessary for the heart, but dangerous regarding other organs (category B). However, conceptions that chronic drug intake could damage the normal function of organs and even lead to disease were also found (category C). Most statements were considered as category B.

Paper IV

A summary of the phases of analysis and the findings obtained is shown in Figure 1. The aim was to investigate spouses' experiences of the rehabilitation phase of their partners' CHD, with particular focus on their views about support for lifestyle changes. The questions aimed at exploring the spouses' reasoning about how support was provided regarding lifestyle changes. The initial question put was 'In what way were you able to support your husband/wife after the event of CHD?' Follow-up questions regarded support in situations related to the same domains as in paper III.

The main aspects discerned were 'support', 'communication', and 'attitudes to lifestyle changes'. These illustrated the spouses' approach in supportive situations. The aspect 'support' was complexly built up by components considered as supportive or not supportive. These can be described by adjectives referring to the type, style, and capacity to support: *practical, cognitive, passive, incapable, controlling, and reluctant*. The components building up the aspect 'communication' were *encouraging/listening* and *authoritative/admonishing*.

The corresponding components building up the aspect ‘attitude to lifestyle changes’ were *positive or negative*.

The analysis of the internal relations between the main aspects and components, as described in each narrative, gave five different views of spouses’ role: the participative role, the regulative role, the observational role, the incapacitated role, and the dissociative role.

The participative role involved taking a practical part in lifestyle changes, communicating empathetically, and being positive about changes. Key words that illustrated this role were cooperation, respect, and mutuality. Collaboration in decision-making, dialogue, and encouragement were other expressions.

The regulative role was characterised by being either positive or negative to changes, giving practical or cognitive support to control the partner’s behaviour, and communicating authoritatively. This role could be featured by the following expressions: enforcement, efforts to find mutuality, admonishing communication, and traces of anger. Self-centred, monologue, prohibition, propaganda, and making of remarks were other linguistic expressions found in this category. More attributions of this style regarded feelings of resignation when the support failed. Also fear of changes being realised and attempts to restrain the partner were found.

The observational role featured a passive style, complying with suggestions, and communicating empathetically. Typical key words illustrating this role were participation, dialogue, listening approach, awareness of beneficial changes, and a positive or negative attitude to changes.

The incapacitated role involved a positive attitude to changes, communicating without making demands, but being unable to provide support due to personal problems. Other typical features were dialogue style of communication, awareness of own limitations, as well as own need of support.

The dissociated role entailed being negative about changes and authoritatively declaring a reluctance to be involved in the partner’s change of lifestyle. This role was also featured by unwillingness to support, lack of knowledge about benefits of changes, and monologue style

of communication. This role was found in relation to food choices, physical exercise, and smoking.

The spouses adopted different roles depending on the supportive situation. A few described similar support regarding diet, physical activity, and stress. Some other spouses used similar approaches concerning diet and physical exercise and regarding physical exercise and smoking, respectively. However, most spouses used varied roles for different domains. The participative role was the most prominent category, as it was assumed in at least one domain by an important part of the spouses. Diet, stress, and physical exercise were the common domains. The regulative role was also prominent. The observational role, the incapacitated role, and the dissociative role were less prominent. The latter role was related to diet, physical exercise, and smoking.

Paper V

The aim was to explore how men and women in the rehabilitation phase of CHD experienced constraining and facilitating factors related to lifestyle changes of importance for wellbeing and prognosis of the disease. The semi-structured interview guide covered five domains: physical exercise, diet, stress, smoking, and drug treatment. The findings portray the patients' different experiences of facilitative and constraining factors to handling lifestyle changes. These factors were regarded as incentives for change. By analysis of interview data across all interview domains, four main categories emerged: *somatic incentives*, *social/practical incentives*, *cognitive incentives*, and *affective incentives*. These were built up by a number of subcategories as described below.

Somatic incentives were characterised by two subcategories: direct and indirect bodily signals indicating improvements or illness. The former signals enhanced awareness of the biological state of the body. The signals functioned as incentives for behaviour change irrespective of whether the experience was negative or positive. Examples of signals were pain and wellbeing. However, direct somatic signals were experienced to constrain behavioural changes. Such signals related to physical inability, side effects of drugs, and bodily imbalances. When signals indicating illness or disturbances were lacking, behavioural change was sometimes considered unnecessary. Indirect somatic signals featured results of tests and measurements confirming ill health or improvements. Such signals could also be constraining, e.g. increased weight leading to more eating as a consolation.

Social/Practical incentives comprised three subcategories: shared concerns, changed conditions, and external environmental factors. All domains were positively or negatively affected by the social context apart from drug treatment, which was only positively viewed. The first subcategory featured active participation, emotional support, either physically or verbally, in the change. Correspondingly, change was experienced as constraining, when commitment was low or lacking. The patients sometimes had different priorities compared to his/her social network in these cases.

The second subcategory involved working conditions, social security issues, and changed conditions within the family. Experiences such as decreased demands and changes, which could ease time-related concerns, facilitated behavioural changes. Increased demands due to problems related to family, economy, and work had a constraining influence. Personal tragedy was another example of problems that hampered the ability to change lifestyle. The last subcategory implied access to facilities for physical activity in the patients' immediate and concrete context as convenient. Adjustments to smoking restrictions at public places facilitated behavioural change as well.

Cognitive incentives were characterised by three subcategories: active decisions, passive compliance, and routines and habits. Own insights, reflections, and appraisal facilitated active decisions. In addition, the need to take responsibility in life facilitated behavioural change. Consideration of demanding situations and viewing CHD as a serious life event was expressed as an incentive for action. The second subcategory featured minor reflections and limited insights of beneficial changes. Authoritative beliefs and demands from health care staff worked in a facilitative manner. Creating routines, e.g. by scheduling activities and considering regularity, simultaneity, and planning as important concerns, facilitated behavioural change. However, an old routine could have a constraining effect, as did changes that involved the need to remember something on different occasions during the day.

Affective incentives entailed three subcategories: fears/reluctance, self-esteem and limitations, and immediate satisfaction of needs. In the first subcategory, fears for health problems and death related to CHD facilitated behavioural change. Negative emotions, e.g. lacking control due to unmet needs of safety worked in a constraining manner. Lifestyle changes were sometimes conceived as a risk for recurrence. Reluctance to change was also expressed. The second subcategory involved decreased self-esteem due to e.g. feelings of declination and

inability to manage important life situations. The final subcategory featured inability to resist temptations. Needs of consolation and to satisfy cravings and rest were stronger incentives than the will to change behaviours. Such feelings were found regarding changes in physical exercise, diet, and smoking.

Distribution of statements in categories and domains

Data are given in Table 4. Cognitive and social/practical incentives were the categories that most frequently facilitated lifestyle changes. In the former category, more than six times as many positive as negative statements were found. The positive statements were particularly related to physical exercise and tobacco. Social and practical incentives were mostly regarded as positive and were linked to changes pertaining to physical exercise and diet. Somatic incentives affected lifestyle changes negatively and positively to the same degree. However, they constrained physical exercise greatly in the subgroup studied. The cessation of the use of tobacco was positively affected by all categories, and mainly by somatic incentives. Drug treatment was facilitated by cognitive incentives, while incentives in the other categories rarely or not at all affected this domain. Those referred to as constraining lifestyle changes were affective, somatic and social/practical incentives.

Table 4. Distribution of statements from 40 interviews at T1 pertaining to each category of the five domains

Categories	Somatic incentives		Social/Practical incentives		Cognitive incentives		Affective incentives	
	+	-	+	-	+	-	+	-
Instances Pos/ Neg								
Physical exercise	5	17	18	7	17	1	-	7
Diet	4	1	22	2	15	2	6	8
Stress	2	-	12	6	7	1	8	6
Tobacco	16	4	11	1	11	1	13	7
Drugs	-	2	5	-	27	4	-	-
Total	27	24	68	16	77	9	27	28

DISCUSSION

DISCUSSION OF FINDINGS

Main findings

The main findings of this thesis showed that the patients' understanding of their illness and its treatment varied considerably and was typically fragmentary. The spouses' understanding of these matters and the causes of coronary heart disease (CHD) were generally on a similar level. Spouses seemed to play a considerable role in supporting their recovering partners and their roles exhibited variations related to the domains studied. The patients' statements about facilitating and constraining factors to achieving change of lifestyle emphasised the great complexity of this process. The importance of social support and network was emphasised and interactions from health care services were only one of several components in this process.

Patients' perspective

The nature of coronary heart disease and risk factors

The patients' understanding of CHD was weak and more fragmented than expected given that the patients were offered secondary preventive activities, including verbal and written information about CHD and its treatment. However, most patients expressed vague descriptions and displayed difficulties in articulating answers about the nature of CHD (I). This may be explained by the fact that patients seem to construct prototypes of their disease (107). Such prototypes have been found to be constituted of symptoms and other attributes associated with the disease rather than linked to the disease itself. When patients experience somatic symptoms, they interpret these by retrieving examples of various diseases from their memory. Correspondingly, the patients' answers concerning ways to avoid future CHD included actions against both relevant risk factors and those of minor or no importance (II). CHD was in these cases sometimes considered as unavoidable by referring to fate and heredity. A similar pattern was found among patients nearing discharge after their first MI, as an important part of them considered MI as impossible to prevent (108). Such conceptions have been found to negatively affect lifestyle changes (73).

As reviewed in the introduction, patients' understanding of the causes of CHD has been investigated previously (67, 69, 109). These investigations also showed that the patients displayed difficulties in articulating causes for CHD and misconceived the effects of unhealthy behaviours. Peri- and post-menopausal women were also unaware of risk factors and symptoms of CHD and even denied the presence of this disease following diagnosis and treatment. A gap between these women's desire for understanding and their ability to access and assimilate knowledge in key areas regarding CHD and personal health behaviours was also identified (110). This seems to be a general way of reacting. Another example has been found among adults with congenital heart disease, who were shown to have a poor understanding of their heart defects (111). However, there are contradictory findings in this area, as qualitatively good knowledge about blood cholesterol has been reported (68).

Lifestyle changes and drug treatment

In the present studies, the patients' descriptions of benefits of lifestyle changes and treatment one year after the episode of CHD did not give the impression of being based on a solid understanding of the importance of such changes. Misconceptions regarding the influence on health of fat intake, smoking, and physical activity were found (II). In another study, smoking was well recognised as a risk factor by smokers, but few of them related this habit to their own MI (108). Another investigation of middle-aged men after an uncomplicated MI also reported that the patients had misconceptions regarding lifestyle changes. For example, almost half of the investigated men believed that physical exercise was dangerous and should only be performed under medical supervision (112). It has also been shown that even if patients cited relevant causes of CHD, e.g. smoking, overweight, and inactivity, their awareness of the association between these risk factors and MI was poor. This was disappointing, especially as their level of satisfaction with cardiac rehabilitation (CR) and education was high (108).

The patients in this thesis rarely linked co-operation with treatment to improvement of their prognosis. Most patients did not fully understand the impact of their drugs, which was exemplified by unspecific and less elaborated statements of their main effects. Patients' views of their medication may have consequences for how they cope with the treatment. Fears and negative images, e.g. that all medicines could be carcinogenic, were found in another study of a general practice population in the UK in (113). A theoretical basis for patients' reasoning may be offered by Leventhal's SRM. The appraisal stage of SRM means that the patients involve specific criteria to estimate the success rate of their coping actions (74). Leventhal

viewed the patient as an active problem solver, and implied that emotional reactions may be provoked at any time of the three stages of his theory, which was constructed using both episodic memories and semantic memories. The former comprised autobiographical memories representing the patients' past experiences and the latter reflected the patients' general and abstract understanding of disease concepts. The episodic memories of prior illness may lead to expectations that patients will experience symptoms when sick, and that drug treatment will facilitate the elimination of symptoms and cure the disease (74). This line of reasoning matches the patients' statements in this thesis. They viewed improper concordance with drug treatment in a variable way, e.g. as a risk for relapse, as a reason for insecurity, or as harmless due to lack of symptoms. The latter view may, according to the SRM, lead to judgements by the patients of inappropriate co-operation with preventive actions, and that the patient may stop the treatment when feeling in good health (74). However, contradictory findings exist, as patients with asymptomatic ischemia were found to be significantly more concordant with an aspirin regimen compared to those with frequent anginal episodes (114).

Incentives for lifestyle changes

Paper V showed a pattern of four main categories and subcategories, which illuminated facilitating and constraining incentives for lifestyle changes during the patients' rehabilitation phase. *Somatic incentives* could function both constrainingly and facilitatingly. Direct and indirect somatic signals were stated as important for intended, as well as established behaviour. A substantial proportion of the patients considered this incentive as negative, which reflected physical problems related to exercise. Others have also found that somatic experiences affected physical exercise negatively (115). However, these constraints did not necessarily come from cardiac symptoms, as problems from legs and joints were also mentioned as a hindering factor. Physical response patterns, cardiac and non cardiac, were found to constrain physical exercise among a variety of patients studied (59, 116). This could be a possible explanation for the low readiness to participate in exercise.

The significance of support by the family and significant others during recovery from CHD was an important finding in this thesis (IV, V). The category *social/practical incentives* included a large relative proportion of positive instances compared to the somatic and affective incentives (V). One aspect that was experienced to positively affect lifestyle changes was shared concerns within the family, which is in accordance with other studies. Thus, peer support motivated physical exercise (117). Useful discussions with wives and pre-existing

quality of marriage were positively associated with the patients' recovery six months after an MI (86). The latter study also showed that these patients engaged their wives as active partners during recovery and were less likely to hide their negative feelings or give up in disagreements to calm their wives (86). The present study also found that feelings of decreased demands, due to changed conditions within the family, facilitated lifestyle changes (V). This finding supports the argument that a feeling of control (56) promotes behavioural change.

Statements made by patients in the present study showed that the social network could also constrain lifestyle changes (V). For example, this was the case when commitment to changes was low or lacking or when severe problems existed within the family context. Such barriers were also identified in another study, which showed that unwillingness of male spouses or children to follow the patient's diet was a common complaint and sometimes the woman had to cook two meals (117). Such a negative strategy can lead to conflicts between the patient and the family (79). Statements illustrating different priorities as constraining were also found in our study (V). Another experience was that life strains, e.g. a divorce or a bereavement in the family, hampered managing smoking cessation (V). This finding is in accordance with the results of Gulanick et al. (117), who reported that several patients admitted resuming smoking due to stresses, e.g. a daughter getting divorced or a wife's death.

Practical incentives to lifestyle change concerned tobacco and physical exercise. Smoking cessation was facilitated by adjustments to non-smoking areas and physical exercise was constrained by lack of access to sporting facilities. The latter issue is supported by a previous study (59). The present study also found that retirement and sick leave facilitated lifestyle change. The reasoning displayed may be incorporated in Leventhal's SRM, which includes an action plan, i.e. a coping stage (74). Thus, patients planning to perform a change in behaviour may experience a restriction or a choice coerced by authorities as helpful. Sick leave or retirement can imply an opportunity for change by creating time for self-instigated change.

Cognitive incentives to lifestyle changes including aspects such as reflections, knowledge, demands, habits, and the establishment of routines functioned facilitatively according to the patients. This category was most often considered to affect lifestyle changes positively. Ben-Sira and Eliezer also found that the cognitive dimension played an important role in the structure of readjustment after an MI. Understanding of the disease seemed to be the resource

that was most strongly associated with coping with habit-breaking demands (52). Similar findings were discovered in another qualitative study among patients, who had undergone a percutaneous coronary intervention (117). This study also confirmed the finding in the present study about occasional deviation from diet advice serving as a facilitator for maintenance of the change. Another study that emphasises the importance of understanding deals with the link between education and health. According to Kaplan and Keil, the socio-economic status of individuals has been shown to affect all-cause mortality. Education is one important component in this respect. In their review they found a strong association between educational level and mortality. Men aged 45-64 with 7 or fewer years of education had a 1.96 times higher risk of death compared to those with 12 or more years of education, and those with 8 to 11 years of education had 1.6 times the risk. The corresponding figures for women were 1.47 and 1.23 (12). In the present investigation, the patients also reflected upon and appraised old habits and ways of handling e.g. stressful events, which was a cognitive way of dealing with changes. This kind of management helped the patients to change their behaviour, as expressed by themselves.

Passive obedience was another cognitive incentive for lifestyle changes and stated as facilitative for compliant behaviour. Such reasoning may be consistent with the theory of reasoned action (TRA), which includes individual factors that may determine the likelihood of the performance of a behaviour (55). The feeling of trust in drug prescriptions and advice from the doctor was one example of passive compliance that worked facilitatively (V). This may be explained by the patient's 'subjective norm', included in the TRA (55). The subjective norm is determined by the individual's normative beliefs, and whether important referents such as doctors agree or disagree about performing a behaviour, weighted against his or her motivation to co-operate with those referents. Several patients considered CHD as a threat to health and as an important event in their lives (V). This way of thinking is in agreement with the health belief model (HBM) (57). According to this model, people must feel threatened by their current behaviour for behaviour change to succeed.

Cognitive incentives could also constrain changes on account of forgetfulness, the need for action by the patient several times per day, and previously established routines. Patients who expressed such thoughts may view their disease and its treatments as being of less importance compared to those actively engaged in behavioural change. This reasoning fits with the HBM, which implies that the change in behaviour, e.g. adjusting to several dosages of medication

per day, does not result in a valued outcome. The patient might think that the effort needed exceeds the expected benefit of the change. A prolonged effect of this can naturally imply negative consequences due to non-concordance with the treatment. Some patients expressed a passive attitude with limited insights into their problems, and experienced demands for lifestyle changes as forced upon them, while others, who were judged to have an appropriate understanding, seemed to take an active decision regarding changes. This is again applicable to Leventhal's self-regulative model (SRM) (74). The patients' experience of constraints (V) may be due to the cognitive representations of their health threats, which included components such as possible consequences of CHD. Other constraining representations might be due to the inability to ease the behavioural changes, e.g. by appraisal of their success.

Affective incentives included aspects such as control, willingness, and self esteem (V). When the patients' need of safety and to gain control was satisfied, lifestyle changes were eased. The theory of planned behaviour (TPB) includes a construct dealing with control beliefs (56). According to this theory, the experience of control over the situation is an important predictor for the intention of performing a behaviour. This may be a way to explain why the affective incentives played an important role among some patients. Blanchard et al. showed that attitudes, subjective norm, and conceived control explained over half of the variance in intention to exercise among patients in CR, while intention explained 23% of the variance in concordance with exercise about four weeks after discharge from hospital (118).

The patients in paper V expressed fears for their health or of death due to their CHD. This was expressed as facilitating behavioural change, which may be theoretically understood by the TPB, in that the possibility to improve an unhealthy lifestyle can function as a way of achieving control of the CHD (56). Emotions such as decreased self-esteem, fear, lack of control, reluctance, limitations, immediate satisfaction of needs, and desire for consolation affected the behavioural change, especially stress management, negatively (V). Experiencing the disease as a threat, and also feeling endangered by the lifestyle change, also worked constrainingly (V). This was in respect of lack of medical safety during exercise, and can be explained by the TPB, as the feeling of control was deficient (56). Reluctance to change may represent a belief that the patient did not feel sufficiently vulnerable or threatened by the disease. The disease episode may not have been experienced as severe, and the possible health gains from a behavioural change did not exceed the perceived constraints linked with the alteration. Such a way of thinking fits with the HBM (57).

Spouses' perspective

Spouses or significant others are the patients' closest social environment. From this point of view it is reasonable to assume that spouses have an impact on their partners' conceptions and behaviours. This opinion was also held by Burke et al., who suggested spouse support to affect concordance in behavioural change (47).

Causes of coronary heart disease

The spouses' understanding of causes of CHD (III) consisted of correct conceptions of several aetiological factors. Knowledge varied within the interview domains, and the best understanding was shown in respect of the effects of fat intake. This assumption was made since the spouses' conceptions were in line with established knowledge in the field (119). The understanding displayed was less developed in the other interview domains. A commonly expressed concern was the view of physical exercise as a risk factor for CHD. Another study, also reflecting the patients' perspective, showed that fear of reinfarction was a constraining factor for physical exercise (59). This is a misconception of a relatively complex set of causal physiological relationships. A prospective study of primary prevention of post-menopausal women free of diagnosed CHD at baseline reported that both walking and vigorous exercise were associated with lower risk of cardiovascular events (120). On the other hand, Shepherd et al. stated that the relative risk of myocardial infarction (MI) within one hour after strenuous exercise was two to six times higher than that of patients who were sedentary during the same time. This means that the overall benefits of physical exercise in general for preventing CHD overrules the relatively small increased risk of inducing an MI during a single event of exercise. The authors also suggested that the more physically active the individual was, the lower was the risk for acute MI during strenuous exertion (121). A further interpretation of the worry stated by the spouses is that their view could result in too little physical activity among their diseased partners. If the spouse and the patient conceive the risk of physical exercise differently, overprotection, leading to decreased self-efficacy of the patient, might be a possible outcome (122).

Previous studies have shown that both wives and male patients with CHD conceived stress as the main cause of the disease (72). Similar statements applied to about half of the spouses in the present study (IV). This misconception may reflect the sources of information mostly

used. An investigation by Murray et al. (69) reported that the couples studied expressed that the main sources of information about cardiovascular risk factors were the popular media and other people, such as friends and neighbours, rather than doctors or nurses. Such publications constantly referred to stress as the cause of CHD (69).

Few of the spouses in paper IV and their partners were smokers, which may explain why the spouses rarely related this habit to the development of CHD. It has previously been found that spouses underestimated the negative consequences of smoking (69). This may have implications for the patients, as the conceived beliefs of others have been shown to directly influence patients' attitudes to smoking (60).

Drug treatment

An ambivalent view regarding benefits vs. negative consequences of drug treatment was found (III). Most spouses conceived the drugs as necessary for the heart, but misconceived them as harmful for other organs and also stated that the treatment could cause cancer. The TRA acknowledges the term 'subjective norm', and is assumed to predict behaviour (55). A negative outcome for the patients may result if spouses or significant others view the treatment as harmful, and the patients rely on and adjust to such conceptions. On the other hand, if the spouse views the treatment positively, this may affect the patient to be more concordant with the treatment.

All spouses in the present study had opinions about their partner's drug treatment, but spouses' conceptions regarding drug treatment seem to be neglected in the literature, as previous data could not be found. Leventhal stated that patients view their illness around five themes, of which causes and cure/control are two. As the media have been shown to affect couples' conceptions of causes of CHD (69), this source of information may have an impact on their conceptions regarding treatment as well.

Social support

Study IV showed five main categories that portrayed spouses' roles. These were associated with important, qualitative differences in the ability to support the recovering partner. The roles illustrated different perspectives on support, but, surprisingly, no spouse acted in the same way in all domains studied. Thus, it seemed that different situations needed different approaches and that the spouses' strategies differed in the actual situations, depending on the

patients' need and willingness to accept support or advice. The present findings were based on a pattern of internal relations among three main aspects: spouse support, communication with the partner, and attitudes to lifestyle change. These aspects have previously been found to have an impact on behavioural change and recovery. For example, emotional and practical support from spouses was positively linked with self-esteem and mastery after an MI (52). An open marital communication and high level of disclosure had significant, positive effects on rate of re-hospitalisation compared with relations where patients did not disclose information to their spouses (88). Fishbein has claimed that attitudes to behavioural changes determine behavioural intentions. Behavioural intentions in turn have been found to predict behaviour (55).

The aspects that built up the spouses' roles may have a strong impact on the patients' recovery and concordance with different regimens. However, the outcome seems to depend on the patients' abilities (123). Coyne and Smith claimed that the process of recovery imposes complex demands on both patient and spouse. Moreover, adjusting to an MI may depend on how the couple can work together (86). The participative role exhibited an effort to provide support (IV). This role involved taking a practical part in lifestyle changes, communicating empathetically, and being positive to changes. Such characteristics match those reported in another study (86) in which patients were able to meet specific challenges and also engaged their wives as active partners in this process. These patients also had the benefits of adequate information about how to handle the disease, and reported the benefit of a good marriage before the MI occurred. In the present investigation the regulative role aimed at facilitating the recovery of the patient, but used demands and prohibition in the communication style (IV). Stewart reported that patients who were approached with control felt overprotected by their spouses (79). These patients suggested that more information would reduce the spouses' fear and anxiety, which were key stressors for the patient (79). Another investigation found that spouses' ability to handle the situation could influence the patients' ability to adapt physically and emotionally to life situations after an MI (85).

The dissociated role was self-centred, and did not aim at supporting the partner (IV). This was characterised by being negative to changes, and authoritatively declaring a reluctance to be involved in the patient's change of lifestyle. The unwillingness to support was also accompanied by lack of knowledge about the benefits of changes. Traces of hostility were also distinguished. Such emotions have been found to correlate with low capacity to handle

lifestyle changes and emotional stress among men with CHD (124). The incapacitated role was also self-centred and implied an inability to provide support to the patient, but communicated and displayed a positive attitude to lifestyle changes (IV). A possible interpretation of the two latter roles might be that the spouses used a handling style that helped them to manage their own stressful situation, i.e. dealing with their partners' life threatening illness. The spouse might have considered the illness as a threat, both to health and current lifestyle. Leventhal and Cameron stated that people constructed different conceptions of the same illness threat and saw different action plans as appropriate for the control of the threat (74). The same person could conceive the same illness in different ways and times, and, therefore, chose alternative ways of handling with it (74). A further interpretation of these roles may be that patients who lack different types of support (emotional, cognitive, and instrumental) seem to show poorer recovery than patients who felt that they had support (125). This has been confirmed by several investigators, who have found that CHD patients, who were unmarried or had less developed social networks, displayed a greater risk of death and new episodes of CHD (81-84). Such patients also had a poorer psychosocial recovery compared to patients who had such needs satisfied (125).

Spouses adopting participative, observational, and incapacitated roles also adopted a dialogue style of communicating the importance of life-style changes. The first two roles were empathetically centred, while the latter was self-centred. Encouragement and open communication have been shown to be of importance for readjustment after an MI (52).

Dimensions involved in cardiac rehabilitation

Meta-analysis of findings

A meta-level picture of the results of this thesis is provided in Table 5, where the findings are collated and viewed within a psychosocial, theoretical framework. Three different dimensions of human needs, i.e. the affective, the cognitive, and the instrumental, respectively, have been pointed out as fundamental for psychosocial readjustment after chronic diseases (52, 79, 126, 127). Analysing the patients' resources within these areas is a possible start for the rehabilitation process, both from the perspective of the patients and from that of the health care professionals, to achieve an optimal autonomy of the patient regarding how to deal with the new situation. Various supportive approaches will also be necessary from spouses and

significant others in the patient's social milieu. The variables displayed in Table 5 will be analysed with inspiration from Ben-Sira's and Eliezer's comprehensive framework, which aimed at predicting factors that enhance or constrain readjustment after an MI (52). Their investigation revealed a 'structure' of various demands constraining readjustment, but also self-controlled resources in handling demands, and the significance of the spouse as a resource. The structure was expanded by the involvement of the trilateral conceptualisation of readjustment, which will be used in the discussion as follows.

The first basic need shown in Table 5 regards the affective dimension, which involved feelings as individual resources concerning aspects such as control, will, and self-esteem (V). Different components facilitated or constrained lifestyle changes within this dimension and a way to intervene against such obstacles could be to focus on the patients' emotional resources concerning the capability of dealing with e.g. fears, limitations, and lack of control. Ben-Sira and Eliezer claimed that convalescents after an MI could constantly be in a state of fear of a recurrent MI, and that psychosocial constraints could cause a disabling reaction to the cardiac disease. Effects of such barriers were negatively linked to the affective readjustment, i.e. mastery and self-esteem (52). Paper V showed that the social network is an affective dimension of individual resources of importance for lifestyle changes and, hence, emphasises the importance of involving the social network in patient care when appropriate (V). However, non-participation, conflicting priorities, and personal tragedies within the family constrained lifestyle changes, which also calls for a sensitivity regarding the actual supportive resources of the social network. The crucial role of the spouse in the readjustment after an episode of CHD was also highlighted in paper IV and in Ben-Sira's and Eliezer's framework (52). They found that the value of spouse support was almost equal to that of the self-controlled resources, e.g. understanding of the disease and self-esteem.

The cognitive dimension in study V involved conceptions and beliefs as individual resources. Although passive compliance was found to affect lifestyle change positively, it is reasonable to assume that a reflected understanding might be more functional from a theoretical perspective, since it involves a higher degree of self-controlled resources. The findings in papers I and II also display the need of cognitive support to the patient. Ben-Sira found that understanding of the disease was a resource more important for readjustment than SES, education, and age (52). Thus, it seems that processes leading to new conceptions, beliefs, and appraisal are required for the readjustment of the CHD patient.

The instrumental dimension in study V involved environmental, financial, and physical resources of importance for the rehabilitation of the patients in the planning of rehabilitation interventions. In order not to overlook these factors, interventions should encompass and involve family/significant others and relevant institutions in society. Functional and physical needs require support from various healthcare professionals. However, according to Ben-Sira, instrumental resources did not predict readjustment to the same degree as the cognitive ones (52).

The presented findings on patients' and spouses' knowledge of CHD, its causes, and treatment may be looked upon as discouraging. However, evaluated differently, the outcome may be of importance for renewal of patient care and of education of patients and spouses. A variety of incentives experienced to affect lifestyle changes during the rehabilitation phase of CHD were identified. The origin of these incentives may be explained by different theories/models developed to predict behavioural change after an episode of a chronic illness (55, 57, 74). Tailoring the education by starting from their experiences and pre-understanding may enhance the possibilities to strengthen co-operation with drug treatment and lifestyle goals.

Table 5. Meta-perspective on variables experienced to affect lifestyle changes

Basic needs	Individuals' resources	Aspects affecting lifestyle changes	Constraining components	Facilitating components
Affective	Feelings	Control Will Self-esteem	Fears, threats, lack of control, reluctance, limitations, immediate satisfaction of needs, consolation	Safety, gaining of control, fears, threats
	Social network	Shared concerns Changed conditions	Non-participation Conflicting priorities Personal tragedies	Active participation Adjustment to needs Changed family conditions
Cognitive	Conceptions Beliefs	Knowledge Demands Routines Habits	Forgetfulness Activation several occasions/day Old routines Lack of habits	Active decisions Responsibility Reflections and appraisal Distance to demands Passive compliance Schemas and habits
Instrumental	Environmental Financial Physical	External environmental factors Economy Direct and indirect signals of disease/ insufficiencies	Costs Physical inability, side-effects of drugs, tiredness, pain, no experience of signals indicating ill-health	Social security system Environmental restrictions Easy access to facilities Pain, well being, taste, sense of immobilisation

Implications for self-care

The patients' and spouses' perspectives on CHD, lifestyle changes, and drugs revealed several important findings to be considered in patient self-care. According to Leventhal, patients need to understand the nature of their disease, as they are active problem solvers and think about the identity of their disease, its timeline, causes, consequences, and cure (74). Health related decisions are linked to these phenomena and, therefore, affect the actions of the patients and the spouses. The patients' conceptions about the nature of their disease displayed a varying

degree of understanding (I). A hypothesis could be that patients with a more comprehensive understanding might also be more co-operative with drug intake positively affecting thrombosis and other underlying mechanisms of the disease. On the contrary, improper concordance might be the case, if the patients can only give representations of CHD as symptoms, especially when symptoms are lacking (74). The same reasoning might be applied to lifestyle changes.

The patients did not conceive the spouses to impact on their drug treatment in a constraining way (V). However, spouses conceiving that the drug treatment is harmful, as revealed in paper III, might negatively affect the behaviour. All other categories were experienced as positively or negatively affected by the spouse/significant other (V). The outcome of lifestyle change may be negatively influenced by spouses being afraid, reluctant, or having an opinion, through which the patient feels constrained (IV). On the contrary, active participation by spouses adjusting to the patients' needs was experienced as supportive by the patients (V), which once again underlines the importance of the spousal role in self-care of the patients. Furthermore, joining a group of other patients was expressed to affect lifestyle changes positively. This highlights the importance of contacts with assistant voluntary organisations.

The patients referred to the Swedish social welfare system as facilitative for lifestyle changes. Less demand seems to create more time to adjust to the new situation. This indicates the importance of a health care legislation that is based on ethical considerations for human rights, needs, and solidarity, as well as cost effectiveness (128).

Implications for patient education and learning

Patient education programmes with a focus on enhancing the patient's understanding have been reported to facilitate recovery and lifestyle changes (30). The cognitive dimension was found to be important in this context, but the other dimensions (social/practical, instrumental, and affective) should also be considered (V). The patients' options for improvement may be enhanced by paying attention to their basic needs and resources during the rehabilitation phase. This requires an individual-based, supportive education of the patient, performed by well-educated health care professionals and also involvement of the patient's social network when adequate, as also suggested by Winberg (27).

Applying learning theories in patient education seems important when planning such activities (70, 129) (30). An intervention should in a broad sense challenge existing conceptions of the patient and preferably also those of spouses/significant others to facilitate meaningful learning (130). Applying a problem-based learning model in patient education could be a rational and feasible way to enhance effects on variables facilitating learning and self-management of a chronic illness such as CHD (95).

DISCUSSION OF METHODS

Qualitative research approaches originating from the phenomenographic framework were used in this thesis. This research method was chosen depending on the purpose of the studies, and the questions that were asked, as described by Polit (131).

The phenomenographic approach

Over the years, phenomenography has been debated by investigators who have used this research approach (63, 93, 132), and by other researchers who have applied phenomenology, which describes the lived experience (101, 133, 134). The former approach has been questioned regarding its applicability in nursing research by Friberg (135). This article aimed at problematising the concept of context in the perspective of human science to gain understanding of phenomenographical research related to nursing care. The authors concluded that the approach has limited applicability in nursing research when complex phenomena are to be studied. However, Sjöström and Dahlgren argued that phenomenography had at least three areas of application for research in the context of health care. The first area indicated was the ways nursing students conceive central phenomena, while the second regarded understanding of patients' ways of experiencing their disease, its origin, symptoms, and treatment. The third area concerned knowledge about how patients' experience may be used in nursing education (93).

The phenomenographic approach has been compared with phenomenology (136). Marton stated that scientists usually define a research specialisation in terms of its object (134). The object of attention in phenomenography is human experience and human awareness. Phenomenography rests on a non-dualistic ontology, i.e. it assumes that the only world we can communicate about is the experienced world (63). The epistemological assumption is that

individuals differ as to how the world is experienced, and aims at describing the variation of human beings' experiences of a phenomenon (137). The aim is not to discern the essence, but the variation of the aspects that define a phenomenon (70). This was performed e.g. in study IV, where the spouses were asked to reflect upon their way of supporting their partner in terms of lifestyle changes. The outcome space illustrates the variation in supportive roles. The object of attention in phenomenology is the essence of human experience itself. If a phenomenological perspective had been used in study IV, the spouses could have reflected upon what support means for them, and the result would have focussed on the common core of the phenomenon. Thus, phenomenography and phenomenology share the same scientific object, but they do not share theory and methodology (70). Giorgi, on the other hand stated that phenomenography has departed from phenomenology to the extent that it has weakened itself. He argued, if phenomenography was an approach not a methodology, but with methodological elements, and not a theory but with theoretical elements it did not meet the demands of a scientific approach (138), which is an important critique. However, the approach applied in this thesis has several advantages. It offered an opportunity to describe different ways of conceiving the disease and its treatment. Contextual analysis (IV) was also a help in distinguishing different ways of experiencing support, but in a more interpretative and analytical way compared to the other studies (I, II, III). However, phenomenography has received more attention in recent years in health care, e.g. among male patients with heart failure (139), and in the context of receiving and giving information about cancer treatment (140). Previous studies of CHD from the patient's perspective have not been found in the literature.

Phenomenography also has limitations. According to Friberg et al., some phenomenographers have failed to accomplish a contextual view of the life situation of patients (135). The authors claimed the study of patients' conceptualisation in relation to their life situation is not similar to the inquiry into patients' experiences (135). This is reasonable to some extent, as phenomenography has limitations regarding in-depth interpretation. Hermeneutics provides another interpretative approach for the analysis of text, and its applicability in a medical context has been shown recently (141). However, contextual analysis (102) allows a possibility to analyse the transcripts in a more interpretative and analytical way. This was conducted in study IV by the search for the components' significance in the actual support situation.

Reliability

The findings in this thesis have limitations. The experiences of the patients' understanding of CHD, lifestyle changes, and drug treatment reflect a delimited part of these phenomena. The patients and the spouses have greater experience concerning the disease and its treatment than reflected in papers I-III. Several considerations were made to increase the reliability of the present studies. In papers I-IV, a strategic sampling was performed to achieve a variation of important variables, as suggested by Polit (131). Tape recordings were used to obtain primary data, which is considered important when studying active understanding among patients (94). Hand-written notes were also used to collect data, which may be regarded as less reliable than data collected by tape recordings. However, the interviewers carefully prepared how to conduct this procedure, and also met during the process of data collection to discuss the hand-recorded answers. These answers also exceed the number that is usually considered sufficient in qualitative studies, which may be seen to increase the quality of the present data.

Respondent validation, or "member checking" represents one kind of triangulation (142). However, this kind of triangulation involves techniques in which the researcher's account is compared with the respondents', in order to achieve correspondence between these two sets of experiences. This procedure may be difficult, as the findings produced by the researcher are designed for a large audience and may therefore be different from the account of the respondent. This is due to the fact that the researcher and the respondent have different roles in the research process (143). Data triangulation was used to view CHD and its treatment from various perspectives. This type of triangulation involves a comparison of data relating to the same phenomenon, but deriving from different respondents (142), e.g. by involving both patients and their spouses, as in this thesis. The respondents in paper I-IV were interviewed about one year after the event of CHD to obtain their perspectives beyond the initial rehabilitation phase. The interviews revealed difficulties in elaborating reasoning even on a lay level about the issues investigated in paper I-III, despite the interviewers' encouragement to the patients to express their understanding in their own words. The respondents had obviously forgotten the main parts of the information given at the hospital.

In phenomenography, a semi-structured interview is most often the method of generating data (70). This method requires the interviewer to immediately interpret the respondents' answer to be able to decide about further questioning (93). In this respect, there may be a limitation in study I and II, as the interview guide was rather structured, with several questions, which may

have limited the possibility of using probes. However, probes were used where applicable rendering this possible bias to be of little importance.

A process called ‘negotiating consensus’ was performed in all papers of this thesis (105). The purpose was to achieve a reliable and trustworthy analysis of data by involving several investigators in this procedure. Four researchers were involved in this process concerning papers I and II and the corresponding figure for papers III-V were three. The first author of the articles was assigned the main responsibility for exploring a certain domain. A co-examiner read transcripts that were grouped and assigned a preliminary category (I-V). After the negotiating discussion, the other researchers read condensed narratives, which had been chosen to illustrate the category. These investigators were also involved in the labelling step as well as in the contrasting work, which was performed last.

The limited quantitative analysis carried out in the work of this thesis (V) was a way of ensuring that the categories established from the qualitative analysis of transcripts were found in a consecutive sample of CHD patients. The analysis started with the transcripts, as they were assumed to comprise richer descriptions than the notes taken during the interview. Counting frequencies of statements that matched the categories found broadened the understanding of how important a certain incentive was in constraining or facilitating lifestyle changes.

CONCLUSIONS

Study I. The patients' understanding of their disease was weak and fragmented as judged on a lay level and difficulties in expanding answers were displayed. The view of CHD as a disease developing over several years was not expressed. Building patient education based on adult learning and pre-existing conceptions seems important.

Study II. Patients' conceptions about lifestyle changes and drug treatment did not give the impression of being based on a solid understanding of the importance of such changes, as judged on a lay level. Both unrealistic and accurate risk factors for CHD were expressed but not linked to the individual's case. The understanding that concordance with treatments can improve prognosis was seldom expressed. Knowledge about patients' conceptions about treatment seems desirable as a way of improving patient care.

Study III. Spouses' conceptions about causes of CHD and drug treatment after their partner's episode of CHD varied considerably. Understanding of central areas in CR was sometimes insufficient. Misconceptions about secondary preventive drugs were found. The misconceptions revealed might have serious implications for co-operation with treatment, as spouse support plays an important role in the process of recovery of the CHD patient.

Study IV. Spouses' support strategies were contextually bound. Five different roles were identified, which varied considerably with regard to supportive approach, style of communication, and attitude to lifestyle changes. Support could be empathetically provided, characterised by awareness of behavioural changes, dialogue-style communication, and co-operation. Support from a self-centred perspective with authoritative communication, and control of the partner was also found. A family perspective and awareness in health care of the supportive roles of spouses are important in the planning of CR.

Study V. Patients' experiences derived four different incentives that facilitated or constrained lifestyle changes. Cognitive and social/practical incentives were most frequently stated to be facilitating. Somatic incentives were often referred to as constraining. These findings should be considered in contacts with patients and their family members to promote their co-operation with suggested measures for secondary prevention.

IMPLICATIONS

Clinical implications

The quality of care can be improved by making health care professionals aware of patients' and spouses/significant others' perspectives of CHD and its treatment. Using a family approach where appropriate, and making an assessment of the patients' and the spouses/significant others' conceptions/experiences of issues, such as identity, timeline, cause, consequences, and cure/control seems appropriate before starting to educate them. Assessing their pre-existing conceptions and beliefs may reveal an important starting point for education. Confirming or challenging the patients' and the spouses' conceptions may be a way of influencing their thinking, which may lead to a qualitatively better understanding of the causes of CHD, drug treatment, self-care activities and possible ways of handling lifestyle changes.

Implications for future research

The findings of this thesis have revealed a delimited part of the patients' conceptions of CHD and its treatment. There is a need to get closer to the phenomenon 'behavioural change'. Models and theories that have been developed to predict behavioural intentions only explain parts of the assumed behaviour. Adopting a more interpretative analysis to study core beliefs behind motivation, behaviours, and propensities for change are in this respect interesting options. The conceptions of CHD from patients' and spouses' perspectives revealed in this thesis could be incorporated in the development and evaluation of patient education.

The spouses' perspectives on CHD could be broadened by investigating gender differences, and frequencies regarding the supportive roles taken by spouses to CHD patients. It would also be of interest to study this support from the perspective of the partners. A specific and sparsely studied question is spouses' beliefs about drug treatment in relation to chronic illnesses.

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REFERENCES

1. Assmann G, Cullen P, J. F, Lewis B, Mancini M. Coronary heart disease: reducing the risk: the scientific background to primary and secondary prevention of coronary heart disease. A worldwide view. International Task force for the Prevention of Coronary Heart disease. *Arteriosclerosis, Thrombosis, and Vascular Biology* 1999;19(8):1819-1824.
2. The National Board of Health and Welfare, Epidemiology Cf. Statistics, Health and Disease: Causes of Death 2000. [http:// www.sos.se](http://www.sos.se) 12th of June Stockholm; 2002.
3. Smith SC, Blair SN, Criqui MH, Fletcher GF, Fuster V, Gersh BJ, et al. Preventing Heart Attack and Death in Patients With Coronary Heart Disease. *Circulation* 1995;92:2-4.
4. Kromhout D, Menotti A, Kesteloot H, Sans S. Prevention of Coronary Heart Disease by Diet and Lifestyle: Evidence From Prospective Cross-Cultural, Cohort and Intervention Studies. *Circulation* 2002;105(7):893-898.
5. Euroaspire. Clinical reality of coronary prevention guidelines: a comparison of EUROASPIRE I and II in nine countries. *Lancet* 2001;31(357):995-1001.
6. Thomson DR. Awareness of and attitudes to coronary heart disease among the public, patients and family members: The HELP study. *Coronary Health Care* 1998;2(Appendix 4):33-37.
7. Cohen M, Byrne M-J, Levine B, Gutowski T, Adelson R. Low rate of treatment of hypercholesterolemia by cardiologists in patients with suspected and proven coronary artery disease. *Circulation* 1991;83(4):1294 -1304.
8. Ellerbeck E, Jencks S, Radford M, Kresowik T, Craig A, Gold J, et al. Quality of care for medicare patients with acute myocardial infarction: A four-state pilot study from the cooperative cardiovascular project. *JAMA* 1995;273(19):1509-1514.
9. Edwards R. ABC of smoking cessation: The problem of tobacco smoking. *British Medical Journal* 2004;328:217-219.
10. Wilhelmsen L. Effects of cessation of smoking after myocardial infarction. *Journal of Cardiovascular Risk* 1998;5:173-176.
11. Hemingway H, Marmot M. Evidence based cardiology: Psychosocial factors in the aetiology and prognosis of coronary heart disease: systematic review of prospective cohort studies (Clinical Review). *British Medical Journal* 1999;318(7196):1460-1467.
12. Kaplan GA, Keil J. Special report: Socioeconomic factors and cardiovascular disease: A review of the literature. *Circulation* 1993;88(4):1973-1998.
13. Lynch J, Kaplan G, Salonen R, Cohen R, Salonen J. Socioeconomic status and carotid atherosclerosis. *Circulation* 1995;92(7):1786-1792.
14. Jiang W, Krishnan R, O'Connor C. Depression and heart disease - Evidence of a link, and its therapeutic implications. *CNS Drugs* 2002;16(2):111-127.
15. Dusseldorp E, van Elderen T, Maes S, Meulman J, Kraaij V. A Meta-Analysis of Psychoeducational Programs for Coronary Heart Disease Patients. *Health Psychology* 1999;18(5):506-519.
16. Linden W, Stossel C, Maurice J. Psychosocial interventions for patients with coronary artery disease: A Meta-analysis. *Archives of Internal Medicine*

1996;156(7):745-752.

17. Jones DA, West RR. Psychological rehabilitation after myocardial infarction: multicentre randomised controlled trial. *British Medical Journal* 1996;313(7071):1517-1521.
18. Wood D, De Backer G, Faergeman O, Graham I, Mancina G, Pyorala K. Prevention of coronary heart disease in clinical practice; recommendations of the Second Joint Task Force of European and other Societies on Coronary Prevention. *Atherosclerosis* 1998 Oct;140(2):199-270.
19. Yusuf S, Wittes J, Friedman L. Overview of results of randomised trials in heart disease. I. Treatments following Myocardial Infarction. *JAMA* 1988;260(14):2088-2093.
20. ISIS-2 CG. Randomised trial of intravenous streptokinase, oral aspirin, both, or neither among 17.187 cases of suspect acute myocardial infarction: ISIS-2. *Lancet* 1988;2:349-360.
21. The Risk Group. Risk of myocardial infarction and death during treatment with low dose aspirin and intravenous heparin in men with unstable coronary artery disease. *Lancet* 1990;336:827-830.
22. Simvastatin-studygroup. Randomised trial of cholesterol lowering in 4444 patients with coronary heart disease: the Scandinavian Simvastatin Survival Study (4S). *Lancet* 1994;344:1383-1389.
23. The HOPE, Investigators. S. Effects of an angiotensin-converting-enzyme inhibitor, ramipril, on cardiovascular events in high-risk patients. *New England Journal of Medicine* 2000;342(3):145-153.
24. Balady GJ, Fletcher BJ, Froelicher ES, Hartley LH, Krauss RM, Oberman A, et al. Cardiac Rehabilitation Programs - A Statement for Health Care Professionals From AHA. In: American Heart Association; 1994.
25. Grace SL, Abbey SE, Shnek ZM, Irvine J, Franche R-L, Stewart DE. Cardiac rehabilitation I: review of psychosocial factors. *General Hospital Psychiatry* 2002;24:121-126.
26. Wenger NK, Froelicher ES, Smith LK, Ades PA, Berra K, Blumentahl JA, et al. Cardiac rehabilitation: clinical practice guideline no. 17. Rockville (MD): US Department of HHS, Public Health Service, AHCPR and the National Heart, Lung, and Blood Institute; 1995 Oct.
27. Winberg B, Fridlund B. Self-reported behavioural and medical changes in women after their first myocardial infarction: a 4-year comparison between participation and non-participation in a cardiac rehabilitation programme. *European Journal of Cardiovascular Nursing* 2002;1:101-107.
28. Thomas RJ, Miller NH, Lamendola C, Berra K, Hedbäck B, Durstine JL, et al. National survey on gender differences in cardiac rehabilitation programs. Patient characteristics and enrollment patterns. *Journal Cardiopulmonary Rehabilitation* 1996;16(6):402-12.
29. Liberman L, Meana M, Stewart D. Cardiac Rehabilitation: Gender differences in factors influencing participation. *Journal of women's health* 1998;7(6):717-723.
30. Rankin SH, Stallings KD. Patient Education- Principles & Practice. Fourth edition ed. Philadelphia: Lippincott Williams & Wilkins; 2001.
31. Glanz K, Rimer B, Lewis F. Health behavior and health education - Theory, research, and practice. Third edition ed. San Fransisco: Jossey-Bass; 2002.
32. Linde BJ, Janz NM. Effect of a teaching program on knowledge and compliance of cardiac patients. *Nursing Research* 1979;28(5):282-6.

33. Glanz K. Compliance with Dietary Regimens: Its Magnitude, Measurement, and Determinants. *Preventive Medicine* 1980;9:787-804.
34. Oldridge NB, Streiner DL. The health belief model: predicting compliance and dropout in cardiac rehabilitation. *Medicine and Science in Sports and Exercise* 1990;22(5):678-83.
35. Sackett D, Straus S, Richardson W, Rosenberg W, Haynes R. Evidence -Based Medicine - How to practice and teach EBM. 2nd ed: Churchill Livingstone; 1997.
36. Dunbar-Jacob J, Burke LE, Puczynski S. Clinical assessment and management of adherence to medical regimens. In: Nicassio P, Smith T, editors. *Managing Chronic Illness: A Biopsychosocial Perspective*. Washington, DC: American Psychological Association; 1995. p. 313-49.
37. Glanz K. Participation, Retention, and Adherence: Implications for Health Promotion Research and Practice (Commentary). *American Journal of Health Promotion* 1999;13(5 May/June):276-77.
38. Kamwendo K, Hansson M, Hjerpe M. Relationships between adherence, sense of coherence, and knowledge in cardiac rehabilitation. *Rehabilitation Nursing* 1998;23(5):240-51.
39. Horne R. Representation of Medication and Treatment: Advances in Theory and Measurement. In: Petrie K, Weinman J, editors. *Perceptions of Health and Illness Current Research and Applications*. London: harwood academic publishers; 1997. p. 155-187.
40. Kjellgren KI, Svensson S, Ahlner J, Säljö R. Antihypertensive medication in clinical encounters. *International Journal of Cardiology* 1998;64:161-69.
41. Kjellgren K, Ahlner J, Säljö R. Taking antihypertensive medication - controlling or co-operating with patients? *International Journal of Cardiology* 1995;47:257-268.
42. Mullen PD. Compliance becomes concordance: Making a change in terminology produce a change in behaviour. *British Medical Journal* 1997;314(7082):691-692.
43. Mechanic D. *Medical sociology. A selective view*. New York: The Free press; 1968.
44. Becker MH, Maiman LA. Sociobehavioral determinants of compliance with health and medical care recommendations. *Medical Care* 1975;13(1):10-24.
45. Richardson MA, Simons Morton B, Annegers JF. Effect of perceived barriers on compliance with antihypertensive medication. *Health Education Quarterly* 1993;20:489-503.
46. Andrade SE, Walker AM, Gottlieb LK, Hollenberg NK, Testa MA, Saperia GM, et al. Discontinuation of antihyperlipidemic drugs - do rates reported in clinical trials reflect rates in primary care settings? *New England Journal of Medicine* 1995;332(17):1125-31.
47. Burke LE, Dunbar-Jacob JM, Hill MN. Compliance with cardiovascular disease prevention strategies: A review of the research. *Annals of Behavioral Medicine* 1997;19(3):239-263.
48. Burke LE, Dunbar-Jacob J. Adherence to medication, diet, and activity recommendations: From assessment to maintenance. *Journal of Cardiovascular Nursing* 1995;2(January):62-79.
49. Näslund G, Fredriksson M, Hellénus M-L, de Faire U. Determinants of compliance in men enrolled in a diet and exercise intervention trial: a

randomized, controlled study. *Patient Education and Counseling* 1996;29:247-56.

50. Quist-Paulsen P, Gallefoss F. Randomised controlled trial of smoking cessation intervention after admission for coronary heart disease. *British Medical Journal* 2003;327(7426):1254-1257.
51. Sung J, Nichol M, Venturini F, Bailey K, JS. M, Cody M. Factors affecting patient compliance with antihyperlipidemic medications in an HMO population. *The American Journal of Managed Care* 1998;4(10):1421-1430.
52. Ben-Sira Z, Eliezer R. The structure of readjustment after heart attack. *Social Science and Medicine* 1990;30(5):523-536.
53. Svederberg EG. Conceptions behind choice and use of food. *Scandinavian Journal of Nutrition* 1996;40(2 suppl no 31):98-100.
54. Montano DE, Kasprzyk D. The theory of reasoned action and the theory of planned behavior. In: Glanz K, Rimer B, Lewis F, editors. *Health Behavior and Health Education Theory, Research and Practice*. 3rd Edition ed. San Francisco: Jossey-Bass; 2002. p. 67-98.
55. Fishbein M, Ajzen I. Belief, attitude, intention, and behavior. An introduction to theory and research. London: Addison-Wesley Publishing Company; 1975.
56. Ajzen I. Nature and operation of attitudes. *Annual Review of Psychology* 2001;52:27-58.
57. Janz N, Champion V, Strecher V. The Health Belief Model. In: Glanz K, Rimer B, FM. L, editors. *Health Behavior and Health Education Theory, Research, and Practice*. 3rd ed. San Francisco: Jossey-Bass; 2002. p. 45-63.
58. Becker M. The health belief model and personal health behavior. *Health Education Monographs* 1974;2:404-419.
59. Godin G, Desharnais R, Valois P, Lepage L, Jobin J, Bradet R. Differences in perceived barriers to exercise between high and low intenders: Observations among different populations. *American Journal of Health Promotion* 1994;8(4):279-285.
60. Miller P, Wikoff R, Hiatt A. Fishbein's model of reasoned action and compliance behavior of hypertensive patients. *Nursing Research* 1992;41(2):104-109.
61. Fleury J. The application of motivational theory to cardiovascular risk reduction. *Journal of Nursing Scholarship* 1992;24(3):229-239.
62. Marton F. Phenomenography- Describing conceptions of the world around us. *Instructional Science* 1981;10:177-200.
63. Marton F. Cognosco ergo sum- Reflections on reflections. In: Dall'Alba G, Hasselgren B, editors. *Reflections on phenomenography - Toward a methodology?* Göteborg: Acta Universitatis Gothoburgensis. Göteborg studies in Educational Sciences; 1996. p. 163-187.
64. Christie D, Logan R, Lake J, Dutch J. Patient and spouse responses to education early after myocardial infarction. *Journal of Psychosomatic Research* 1988;32(3):321-25.
65. Smith MM, Hicks VL, Heyward VH. Coronary heart disease knowledge test: developing a valid and reliable tool. *Nurse Practitioner* 1991;16(4):28, 31, 35-8.
66. Thomson DR. Effect of In-Hospital Counseling on Knowledge in Myocardial Infarction Patients and Spouses. *Patient Education and Counseling* 1991;18:171-77.

67. Zerwick J, King K, Wlasowicz G. Perceptions of patients with cardiovascular disease about the causes of coronary artery disease. *Heart & Lung* 1997;26(2):92-8.
68. Allen SS, Bache-Wiig ML, Hunninghake DB. Patient perceptions about the influence of cholesterol on heart disease. *American Journal of Preventive Medicine* 1992;8(1):30-6.
69. Murray SA, Manktelow KB, Clifford C. The interplay between social and cultural context and perceptions of cardiovascular disease [Issues and innovations in nursing practice]. *Journal of Advanced Nursing* 2000;32(5):1224-1233.
70. Marton F, Booth S. *Learning and Awareness*. Mahwah, New Jersey: Lawrence Erlbaum Associates, Inc., Publishers; 1997.
71. Wright LM, Watson WL, Bell JM. *Familjefokuserad omvårdnad. Föreställningar i samband med ohälsa och sjukdom*. Original title: *Beliefs: the Heart of Healing in Families and Illness*. Lund: Studentlitteratur; 2002.
72. Arefjord K, Hallaråker E, Havik OE, Maeland JG. Illness understanding, causal attributions and emotional reactions in wives of myocardial infarction patients. *Psychology and Psychotherapy: Theory, Research and Practice* 2002;75:101-114.
73. Petrie K, Weinman J. Illness Representations and Recovery from Myocardial Infarction. In: Petrie K, Weinman J, editors. *Perceptions of Health and Illness Current Research and Applications*. London: harwood academic publishers; 1997. p. 441-461.
74. Leventhal H, Cameron L. Behavioral theories and the problem of compliance. *Patient Education and Counseling* 1987;10:117-138.
75. Peters K, Horne R, Kong F, Francomano C, Biesecker B. Living with Marfan syndrome II. Medication adherence and physical activity modification. *Clinical Genetics* 2001;60:283-292.
76. Steel N. Thresholds for taking antihypertensive drugs in different professional and lay groups: questionnaire survey. *British Medical Journal* 2000;320(7247):1446-1447.
77. Horne R, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research* 1999;47(6):555-567.
78. Kerns RD. Family Assessment and Intervention. In: Nicassio PM, Smith TW, editors. *Managing Chronic Illness: A Biopsychosocial Perspective*. Washington, DC: American Psychological Association; 1995. p. 207-244.
79. Stewart M, Davidsson K, Meade DM, Hirth A, Makrides L. Myocardial infarction: survivors' and spouses' stress, coping, and support. *Journal of Advanced Nursing* 2000;31(6):1351-60.
80. Macken LC, Yates B, Blancher S. Concordance of riskfactors in female spouses of male patients with coronary heart disease. *Journal of Cardiopulmonary Rehabilitation* 2000;20(6):361-368.
81. Chandra V, Szklo M, Goldberg R, Tonascia J. The impact of marital status on survival after an acute myocardial infarction: a population-based study. *American Journal of Epidemiology* 1983;117(3):320-325.
82. Orth-Gomér K, Johnson JV. Social network interaction and mortality: A six year follow-up study of a random sample of the Swedish population. *Journal of Chronic Diseases* 1987;40(10):949-957.

83. Wiklund I, Oden A, Sanne H, Ulvenstam G, Wilhelmsson C, Wilhelmsen L. Prognostic importance of somatic and psychosocial variables after a first myocardial infarction. *American Journal of Epidemiology* 1988;128(4):786-795.
84. Mendes de Leon CF, Apples AWPM, Otten FWJ, Shouten EGW. Risk of mortality and coronary heart disease by marital status in middle-aged men in the Netherlands. *International Journal of Epidemiology* 1992;21(3):460-466.
85. Beach EK, Maloney BH, Plocica AR, Sherry SE, Weaver M, Luthringer L, et al. The spouse: A factor in recovery after acute myocardial infarction. *Heart and Lung* 1992;21(1):30-38.
86. Coyne JC, Smith DAF. Couples Coping With a Myocardial Infarction: Contextual Perspective on Patient Self-Efficacy. *Journal of Family Psychology* 1994;8(1):43-54.
87. Theobald K. The experience of spouses whose partners have suffered a myocardial infarction: a phenomenological study. *Journal of Advanced Nursing* 1997;26(3):595-601.
88. Helgesson VS. The effects of masculinity and social support on recovery from myocardial infarction. *Psychosomatic Medicine* 1991;53(6):621-633.
89. Ell KO, Haywood LJ. Sociocultural factors in MI recovery: An exploratory study. *International Journal of Psychiatry in Medicine* 1985-86;15(2):157-175.
90. Kettunen S, Solovieva S, Laamanen R, Santavirta N. Myocardial infarction, spouses' reactions and their need of support. *Journal of Advanced Nursing* 1999;30(2):479-488.
91. O'Farrell P, Murray J, Hotz SB. Psychologic distress among spouses of patients undergoing cardiac rehabilitation. *Heart & Lung* 2000;29(2):97-104.
92. Alexandersson M. Den fenomenografiska forskningsansatsen i fokus. In: Starrin B, Svensson P-G, editors. *Kvalitativ metod och vetenskapsteori*. Lund: Studentlitteratur; 1994. p. 111-136.
93. Sjöström B, Dahlgren LO. Applying phenomenography in nursing research [Nursing Theory and Concept Development or Analysis]. *Journal of Advanced Nursing* 2002;40(3):339-345.
94. Patton MQ. *Qualitative evaluation and research methods*. 2nd ed. Newbury Park: SAGE Publications; 1990.
95. Tingström P, Göransson A, Kamwendo K, Bergdahl B. Validation and feasibility of problem-based learning in rehabilitation of patients with coronary artery disease. *Patient Education and Counseling* 2002;47(4):337-345.
96. Dahlgren L-O, Fallsberg M. Phenomenography as a Qualitative Approach in Social Pharmacy Research. *Journal of Social and Administrative Pharmacy* 1991;8(4):150-56.
97. Marton F, Pang MF. Two Faces of Variation. In: 8th European Conference for Learning and Instruction 24-28 August; 1999; Gothenburg, Sweden: Gothenburg University; 1999. p. 1-12.
98. Göransson A, Dahlgren LO, Lennerstrand G. Changes in conceptions of meaning, effects and treatment of amblyopia. A phenomenographic analysis of interview data from parents of amblyopic children. *Patient Education and Counseling* 1998;34:213-25.
99. Mårtensson J, Karlson JE, Fridlund B. Female patients with congestive heart failure: how they conceive their life situation. *Journal of Advanced Nursing* 1998;28(6):1216-24.

100. Friedrichsen M, Strang P, Carlsson M. Breaking bad news in the transition from curative to palliative cancer care- patient's view of the doctor giving the information. *Supportive Care in Cancer* 2000;8:472-478.
101. Friberg F. Pedagogiska möten mellan patienter och sjuksköterskor på en medicinsk vårdavdelning - Mot en vårddidaktik på livsvärldgrund. Göteborg: Göteborgs Universitet; 2001.
102. Svensson L. Contextual analysis - The development of a research approach. In: 2nd Conference on Qualitative Research in Psychology; 1985; Leusden, The Netherlands; 1985.
103. Abrandt M. Learning Physiotherapy: The impact of formal education and professional experience. Linköping studies in Education and Psychology, Disseratation No 50: Linköping University; 1997.
104. Svensson L. The Conceptualization of Cases of Physical Motion. *European Journal of Psychology of Education* 1989;4(4):529-545.
105. Wahlström R, Dahlgren LO, Tomson G, Diwan VK, Beermann B. Changing primary care doctors' conceptions - A qualitative approach to evaluating an intervention. *Advances in health sciences education* 1997;2:221-236.
106. Abrandt Dahlgren M. Learning physiotherapy: students' ways of experiencing the patient encounter. *Physiotherapy Research International* 1998;3(4):257-273.
107. Bishop G. Understanding the understanding of illness: Lay disease representations. In: Skelton J, Croyle R, editors. *Mental Representations in Health and Illness*. New York: Springer-Verlag; 2003.
108. Murray PJ. Rehabilitation information and health beliefs in the post -coronary patient: do we meet their information needs? *Journal of Advanced Nursing* 1989;14(8):686-93.
109. Tod AM, Read C, Lacey A, Abbot J. Barriers to uptake of services for coronary heart disease: qualitative study. *British Medical Journal* 2001;323(7306):214-17.
110. Lisk CJ, Grau L. Perceptions of women living with coronary heart disease: A pilot investigation. *Women & Health* 1999;29(1):31-46.
111. Kantoch MJ, Collins-Nakai RL, Medwid S, Ungstad E, Taylor DA. Adult patients' knowledge about their congenital heart disease. *Canadian Journal of Cardiology* 1997;13(7):641-45.
112. Newens AJ, McColl E, Bond S. Changes in reported dietary habit and exercise levels after an uncomplicated first myocardial infarction in middle-aged men. *Journal of Clinical Nursing* 1997;6(2):153-60.
113. Britten N. Patients' ideas about medicines: a qualitative study in a general practice population. *British Journal of General Practice* 1994;44:465-468.
114. Carney RM, Freedland KE, Eisen SA, Rich MW, Skala JA, Jaffe AS. Adherence to profylactic medication regimen in patients with symptomatic versus asymptomatic ischemic heart disease. *Behavioral Medicine* 1998;24(1):35-9.
115. Crane P, McSweeney J. Exploring older women's lifestyle changes after myocardial infarction. *MEDSURG Nursing* 2003;12(3):170-176.
116. Biggs J, Fleury J. An exploration of perceived barriers to cardiovascular risk reduction. *Cardiovascular Nursing* 1994;30(6):41- 46.
117. Gulanick M, Bliley A, Perina B, Keough V. Recovery patterns and lifestyle changes after angioplasty: The patient's perspective. *Heart&Lung* 1998;27(4):253-62.

118. Blanchard CM, Courneya KS, Rodgers WM, Daub B, Knapik G. Determinants of exercise intention and behavior during and after phase 2 cardiac rehabilitation: An application of the theory of planned behavior. *Rehabilitation Psychology* 2002;47(3):308-323.
119. Benjamin E, Smith S, Cooper R, Hill M, Luepker R. Task force#1- Magnitude of the prevention problem: opportunities and challenges. 33rd Bethesda Conference. *Journal of American College of Cardiology* 2002;40(4):588-603.
120. Manson JE, Greenland P, LaCroix AZ, Stefanick ML, Mouton CP, Oberman A, et al. Walking compared with vigorous exercise for the prevention of cardiovascular events in women. *The New England Journal of Medicine* 2002;347(10):716-725.
121. Shephard RJ, Balady GJ. Exercise as Cardiovascular Therapy. *Circulation* 1999;99:963-972.
122. Berkhuysen M, Nieuwland W, Buunk B, Sanderman R, Rispens P. Change in self-efficacy during cardiac rehabilitation and the role of perceived overprotectiveness. *Patient Education and Counseling* 1999;38:21-32.
123. Bandura A. Social Cognitive Theory of Self-Regulation. *Organizational Behaviour and Human Decision Processes* 1991;50:248-287.
124. Fiske V, Coyne JC, Smith DA. Couples coping with myocardial infarction: An empirical reconsideration of the role of overprotectiveness. *Journal of Family Psychology* 1991;5(1):4-20.
125. Kumlin T, Forskningsrådsnämnden. Familjen och hjärtat: En litteraturoversikt. Ord & Form AB, Uppsala; 1998. Report No.: 98:10.
126. Thoits PA. Social Support and and psychological well-being: Theoretical possibilities. In: Sarason IG, Sarason BR, editors. *Social Support: Theory, Research and Applications*. Dordrecht: Martinus Nijhoff; 1985. p. 51-72.
127. Jacobson DE. Types and Timing of Social Support. *Journal of Health and Behavior* 1986;27(September):250-64.
128. SOU-2001:8. Prioriteringar i vården: Perspektiv för politiker, profession och medborgare. Slutbetänkande från Prioriteringsdelegationen. Stockholm: Fritzes Offentliga publikationer; 2001.
129. Knowles MS, Holton EF, Swanson RA. *The Adult Learner. The definitive classic in adult education and human resource development*. 5th ed. ed. Houston, Texas: Gulf Publishing Company; 1998.
130. Tooth L, McKenna K. Cardiac patient teaching: application to patients undergoing coronary angioplasty and their partners. *Patient Education and Counseling* 1995;25:1-8.
131. Polit DF, Hungler BP. *Nursing Research Principles and Methods*. 6th ed. Philadelphia: J.B. Lippincott Company; 1999.
132. Hasselgren B, Beach D. Phenomenology A "good for nothing brother" of phenomenology? Göteborg: Department of Education and Educational Research; 1996. Report No.: 1996:05.
133. Giorgi A. Phenomenology and phenomenography. In: *Fenomenologi, fenomenografi och hermeneutik; Seminarium i Örebro 21-22 aug. Örebro: Forum för humanvetenskaplig forskning; 1997. p. 3-11.*
134. Marton F, Giorgi A. Debatt Ference Marton/Amadeo Giorgi, symposiedeltagarna. In: *Fenomenologi, fenomenografi och hermeneutik; Seminarium i Örebro 21-22 aug. Örebro: Forum för humanvetenskaplig forskning; 1997. p. 20-28.*

135. Friberg F, Dahlberg K, Peterson M, Öhlén J. Context and methodological decontextualization in nursing research with examples from phenomenography. *Scandinavian Journal of Caring Sciences* 2000;14:37-43.
136. Marton F. Fenomenografi och fenomenologi. In: *Fenomenologi, fenomenografi och hermeneutik; Seminarium i Örebro 21-22 aug.* Örebro: Forum för humanvetenskaplig forskning; 1997. p. 12-19.
137. Marton F. Phenomenography: A Research Approach to Investigating Different Understandings of Reality. In: Sherman RR, Webb RB, editors. *Qualitative Research in Education: Focus and Methods*. London: Falmer Press; 1988. p. 141-61.
138. Giorgi A. A phenomenological perspective on some phenomenographic results on learning. *Phenomenological Psychology* 1999;30(2):68-94.
139. Mårtensson J, Karlsson JE, Fridlund B. Male patients with congestive heart failure and their conceptions of the life situation. *Journal of Advanced Nursing* 1997;25(3):579-86.
140. Friedrichsen M. *Crossing the border: Different ways cancer patients, family members and physicians experience information in the transition to the late palliative phase.* Dept of Biomedicine and Surgery, Linköping: Linköping University; 2002.
141. Sveneus F. *The hermeneutics of medicine and the phenomenology of health: Steps towards a philosophy of medical practice.* Linköping: Linköping University; 1999.
142. Hammersly M, Atkinson P. *Ethnography: principles in practice* 2nd ed. New York: Routledge, Taylor & Francis Group; 2000.
143. Mays N, Pope C. Qualitative research in health care: assessing quality in qualitative research. (Education and debate). *British Medical Journal* 2000;320:50-52.

APPENDIX I-III

APPENDIX I

I. Interview guide – paper I and II

1. Can you tell me what happened when you became ill?
 - What diagnosis did you receive at the hospital?

2. Do you have any physical problems? How they appear?
 - When do they occur?
 - Do you know why you have these problems?
 - What happens in the body when you get these problems?
 - What is a heart attack? What happens?
 - What is angina pectoris? What happens?

3. What medication are you on?
 - How does it work?

4. How easy do you find it to follow all the instructions you are given?
 - Medication: Have you occasionally not taken your medicine?
 - What do you think happens if you do not take the medication properly?

5. Diet: Have you received any special dietary advice?
 - Why is it important to eat less fat?
 - Are there different kinds of fat?

6. Physical exercise: Have you received any advice regarding physical exercise?
 - How do you think physical exercise affects you?

7. Smoking: Why is smoking a risk factor for a heart attack?
8. Is it possible to avoid a heart attack?
9. Is it possible to avoid angina pectoris?

APPENDIX II

II. Interview guide – paper III and IV

1. Would you like to tell me what happened when your husband/wife became ill?
2. Has this affected your life? Has it meant any changes in your daily life? In what way?
3. Is there anything that can be done to prevent a relapse? Can you do anything about it yourself?
4. What causes CHD?
5. In what way were you able to support your husband/wife after the event of CHD?

Physical exercise

6. In what way could you support your husband/wife in respect of physical exercise?
 - What does physical exercise mean for the development of CHD?
 - What advantages does physical exercise have in connection with CHD?
 - What disadvantages does physical exercise have in connection with CHD?
 - Do you think physical exercise affects CHD?

Diet

7. In what way are you able to support your husband/wife regarding diet?
 - Does fat affect the development of CHD?
 - Are there any advantages in changing fat intake after CHD?
 - Are there any disadvantages in changing fat intake in connection with CHD?

Stress

8. Do you think stress is a part of your husbands/wife's life? In what way?
 - In what way could you support your husband/wife regarding stress?
 - Do you think stress has any significance in the development of CHD?

Tobacco

9. Does your husband/wife smoke?
 - Do you think smoking has any significance in the development of CHD? Can you explain how?
 - In what way could you support your husband/wife regarding giving up smoking?

Medication

10. What is your view about the medication prescribed to your husband/wife?
 - What advantages do you see with the medication?

- What disadvantages do you see with the medication? Do you know what medicines your husband/wife has? Do you know the specific function of tablet x, y, z?

APPENDIX III

III. Interview guide – paper V

Getting physical exercise can be both easy and difficult

1. What opportunities do you have to perform physical exercise?
 - What makes it easier?
 - What makes it more difficult/what hinders you?

Changing dietary habits can be both easy and difficult

2. How would it be for you to change your dietary habits?
 - What makes it easier?
 - What makes it more difficult/what hinders you?

Giving up smoking can be both easy and difficult

3. What influenced/influences you in your efforts to stop smoking?
 - What makes it easy?
 - What makes it more difficult/what hinders you?

Changing your stress related habits can be both easy and difficult

4. How has changing your habits gone for you?
 - What has made it easier?
 - What has made it more difficult/what has hindered you?

Following a doctor's orders concerning medication can be both easy and difficult

5. How has it been for you to follow prescriptions?
 - What has made it easier? What has made it more difficult/hindered you?
(Beta-blocking drugs; Lipid-lowering drugs)