

**Person-centred care
and self-efficacy -
Experiences, measures and effects after an event
of acute coronary syndrome**

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"I do, indeed, close my door at times and surrender myself to a book, but only because I can open the door again and see a human face looking at me"

Martin Buber

In memory of my brother Thomas, you and I will never die

ABSTRACT

Person-centred care (PCC) highlights the importance of knowing the patient as a person and is a key component in engaging the person as an active partner in health care and treatment to improve illness management. Self-efficacy is a closely related concept to PCC as it refers to peoples' beliefs in their capability to influence events that affect their lives. Acute coronary syndrome (ACS) events are associated with arduous recovery and a PCC approach may facilitate self-efficacy beliefs and thereby improve health and clinical outcomes.

The overall aim of this thesis was to build an understanding of patients' prerequisites to collaborate as partners in their care after an event of ACS and to evaluate measures and the effects of a PCC intervention on self-efficacy and return to previous activity. Moreover, the goal was to identify if a person-centred approach can facilitate the care chain from hospital, outpatient and primary care for patients with ACS.

A multi-method qualitative and quantitative approach was used to gather and analyse data. Study I involved 12 interviews with patients affected by ACS, which were analysed by the phenomenological hermeneutical method. Study II consisted of a confirmatory factor data analysis of cardiac self-efficacy scale (CSES) data from 288 patients with ACS. In Study III, 199 patients with ACS were enrolled in a randomised controlled trial (RCT) evaluating the effects of a PCC intervention in a composite score of changes, including general self-efficacy (GSE), return to work or prior activity level and rehospitalisation or death, which were followed up at 6 months post-discharge from the hospital. Descriptive statistics, non-parametric tests and logistic regression were used to analyse the data. In Study IV, the PCC intervention was evaluated against the CSES in 177 of the 199 patients, who were included in the RCT. Data were analysed with descriptive statistics and parametric tests.

The results showed that patients with ACS formulated personal models built on their understanding of how they recognised, interpreted and responded to their illness early on during the hospitalisation. The Swedish CSES was shown to be a valid and reliable measure to evaluate cardiac self-efficacy (CSE) in patients with ACS. In the RCT, the composite score at 6 months showed that a higher number of participants in the PCC group improved in comparison with the usual care group (22.3%, n=21 versus 9.5%, n=10; Odds ratio=2.7, 95% CI: 1.2–6.2; P=0.015). Separation of the composite score into each individual component showed that GSE improved significantly in the PCC group (P=0.026). At the 4-week follow-up, the PCC group reported improved scores in the symptom control dimension, indicating higher CSE [mean change (standard deviation, SD)=0.81 (3.5)], while the control group reported worsening scores [mean change (SD)=-0.20 (3.0)]. The difference between groups was statistically significant (P=0.049).

The conclusion from this thesis is that patients with ACS formulate personal models which can be integrated into a person-centred dialogue and the development of a personal health plan. Self-efficacy is a valuable concept in PCC that can be used as an outcome measure of PCC interventions. A PCC approach can advantageously be implemented in care of patients with ACS to encourage the improvement of patient self-efficacy without worsening the clinical events.

Keywords: acute coronary syndrome, cardiac rehabilitation, person-centred care, phenomenological hermeneutics, psychometric validation, randomised controlled trial, self-efficacy

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LIST OF PAPERS

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International Journal of Nursing Studies. 2014 Mar;51(3):430-7.
- II Fors A, Ulin K, Cliffordson C, Ekman I, Brink E. The Cardiac Self-Efficacy Scale, a useful tool with potential to evaluate person-centred care.
European Journal of Cardiovascular Nursing. 2014 Aug 22.
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- III Fors A, Ekman I, Taft C, Björkelund C, Frid K, Larsson ME, Thorn J, Ulin K, Wolf A, Swedberg K. Person-centred care after acute coronary syndrome, from hospital to primary care – A randomised controlled trial.
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- IV Fors A, Taft C, Ulin K, Ekman I. Effects of person-centred care on cardiac self-efficacy after acute coronary syndrome – A randomised controlled trial.
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ABBREVIATIONS

| | |
|--------|---|
| ACS | Acute Coronary Syndrome |
| CCU | Coronary Care Unit |
| CFI | Comparative Fit Index |
| CHD | Coronary Heart Disease |
| CI | Confidence Interval |
| CSE | Cardiac Self-Efficacy |
| CSES | Cardiac Self-Efficacy Scale |
| GPCC | Gothenburg Centre for Person-Centred Care |
| gPCC | Gothenburg Person-Centred Care Approach |
| GSE | General Self-Efficacy |
| GSES | General Self-Efficacy Scale |
| ICD | International Classification of Diseases |
| PCC | Person-Centred Care |
| RCT | Randomised Controlled Trial |
| RMSEA | Root Mean Square Error of Approximation |
| RN | Registered Nurse |
| S-CSES | Swedish Cardiac Self-Efficacy Scale |
| SD | Standard Deviation |
| SRM | Standardised Response Mean |
| SRMR | Standardised Root Mean Square Residual |
| SSE | Specific Self-Efficacy |

INTRODUCTION

Social cognitive theory is relevant in health care and health communication as it involves cognitive, emotional and behavioural aspects that allow the understanding of behavioural changes. People perform behaviours that are purposive or goal-directed relying on personal beliefs to initiate and maintain self-care and healthy behaviour (Bandura, 1997a).

Self-efficacy

Self-efficacy is the belief in one's capability to execute the behaviour required to produce desired outcomes (Bandura, 1977, Bandura, 1997b). In previous research, self-efficacy has been reported to play a fundamental part of the social cognitive theory and serve as a basis for successful interventions (Bandura, 1997b). There is a clear difference between a person's assessment that a particular behaviour will lead to a favourable result (outcome expectations) and the conviction of a person to execute the required behaviour in order to achieve the result (efficacy expectations) (Bandura, 1977). Behaviour change or maintenance includes a combined function of both expectations such that the behaviour will lead to a certain outcome and expectations about a person's capability to engage and execute the behaviour. Even if a person believes that their health is their own responsibility, they may still fail to take on the necessary health actions because they lack the confidence in their own capability to perform the required behaviour (Bandura, 1977, Bonetti *et al.*, 2001).

According to the social cognitive theory (Bandura, 1986, Bandura, 1997b), self-efficacy beliefs are related to three dimensions: 1) magnitude (particular level of task difficulty); 2) strength (conviction of successfully performing a particular level of task difficulty); and 3) generality (the extent to which the magnitude and strength beliefs are generalised across tasks and situations). Although self-efficacy is commonly understood as domain-specific there is a growing interest and attention towards a more generalised self-efficacy domain. General self-efficacy (GSE) refers to a person's belief in their ability to influence the outcome in general (Schwarzer R and Jerusalem M, 1995). In contrast, specific self-efficacy (SSE) refers to a given behaviour or situation, such as the belief in influencing the outcome related to a specific disease like coronary disease (Sullivan *et al.*, 1998). Even though GSE and SSE differ in scope, they both deal with a person's abilities to achieve a desired outcome. As such, both concepts are based on self-efficacy.

There are four main sources of self-efficacy: 1) mastery experience (individual experience of successful accomplishment in a specific situation); 2) vicarious experience (seeing someone else succeed in accomplishing a task in a similar situation); 3) verbal persuasion (being encouraged by trusted advisor); 4) psychological and affective states (individual physically and psychologically positive experiences of a behaviour; negative experiences will have a negative effect) (Bandura,

1997b). Accumulations of positive experiences from these four sources enhance self-efficacy. According to Bandura, powerful mastery experiences that provide striking conviction to a person's capacity to influence personal changes can also restructure efficacy beliefs across diverse areas of functioning. Personal triumphs in which a person mobilises the effort necessary to succeed in different undertakings serve as generalising experiences (Bandura, 1997b).

Of note, there are large variations in how people perceive their self-efficacy. However, research has demonstrated that self-efficacy is sensitive to modification and that interventions can enhance self-efficacy, which is associated with improved health behaviours and clinical outcomes (Lorig *et al.*, 2001, Lorig and Holman, 2003, Marks *et al.*, 2005)

Human agency

Social cognitive perspective on human agency refers to Bandura's work on self-efficacy. His definition emphasises ways in which persons exercise control over their lives by acting on their environment in a goal-directed manner. Human agency has internal as well as external determinants. A person's efficacy is dependent on personal factors (e.g. cognitive, affective, and biological), behaviour factors (e.g. skills, practice, motivation, actions, and decisions) and the external environment (e.g. social norms, access in community, culture, and policies) (Bandura, 1997b). According to Bandura, the behaviouristic view that the environment determines a person's behaviour was overly simplistic. He pointed out that the three factors, environment, person and behaviour, are constantly influencing each other. Bandura called this interaction *reciprocal determinism* (Bandura, 1986, Bandura, 1997b).

A person is not a machine without a will. Conversely, persons have the ability to plan, think and predict the results of their actions. Since judgements and actions are partly self-determined, persons can effect change in themselves and their situations through their own efforts. In that process, a key question is how persons can contribute to their own motivation to act, that is, how they can increase their agency and freedom by exercising self-influence (Bandura, 1989). Human agency is purposive, constructive and it involves planning (Bandura, 1997b, Bandura, 2001). If people perceive themselves as more capable of accomplishing certain activities, they are more likely to undertake them (Bandura, 1989). Bandura also refers to "agentic capabilities" or resources, which allow people to be more successful in reaching their goals. In this view, the belief that one is capable of acting meaningfully upon the world, or perceived self-efficacy, is an important characteristic that is a part of, or can lead to, human agency. Without a sense of perceived efficacy, it is unlikely that a person will be motivated to act (Bandura, 2006).

Human agency is characterised by several core features, including intentionality, forethought, self-reactiveness and self-reflectiveness. Intentionality is a represen-

tation of a future course of action. Forethought refers to persons setting goals for themselves and guiding their actions in anticipation of future events. Self-reactiveness is the ability to give shape to appropriate courses of action and motivate and regulate their execution. Self-reflectiveness means that people evaluate their motivation, values and the meaning of their life pursuits. The social cognitive theory considers the environment to be important in determining a person's behaviour. However, at the same time, this theory argues that people can exert substantial influence over their own outcomes and environment more broadly by means of these core features (Bandura, 2001).

Empowerment

A similar notion to human agency is that of individual empowerment, which has received growing attention in the realm of health care. Many professional relations are paternalistic and unbalanced in terms of power (Tengland, 2008). This is also seen in health care where the patient is described as being in triple disadvantage (institutional, existential and cognitive) (Kristensson Ugglå, 2014). Empowerment is a process aimed to create conditions for people to obtain more power over their health and gain improved access to and control over their resources and lives (Rappaport, 1995). Even though the essence of empowerment is *power*, it does not refer to the transferring of power to people (Laverack, 2006). One requirement for empowerment is that the means of the health care professionals are congruent with the empowerment goals, reflected as increased control for the patient. To achieve this, health care professionals need to avoid a dominant position as much as possible by reducing the power, control, and influence over the decision-making process. Instead, health care professionals should elicit and increase the power of the person and/or supporting relatives (Tengland, 2008).

Empowerment is based on the idea that people have the capacity, power, and resources, by virtue of being human beings, to define their own problems and develop action strategies to manage these. This means that the person in need of care formulates the problem, finds solutions and acts in problem-solving, and the health care professionals are supporting and facilitating collaborators in this process. Empowerment aims to identify and bring out the person's inherent power and to encourage them to utilise their skills. It is useful to tackle adversities in life, and develop and achieve goals. Empowerment as a goal is comprised of having control over that which determines the quality of life for the person. As a process, empowerment consists of building a professional relationship in which the person in need of care or the community takes control over the change process, determining both the goals of this process and the means to use it. An increase in self-efficacy typically increases people's control over the determinants of their quality of life, and therefore, often contributes to increase in empowerment. Hence, self-efficacy in relation to specific tasks or situations does not necessary increase empowerment, although every increase in GSE seems to be an increase in empowerment (Tengland, 2008).

Person-centred care

The history of person-centredness in health care goes back to the middle of the 20th century when the psychologist Carl Rogers (1902–1987) laid the foundation of person-centredness as he focused on people's perspectives and experiences of their situation, known as "client-centred psychotherapy" (Rogers, 1951, Rogers, 1961). Later he also used the term "person-centred" to describe interpersonal relations and personalities. Roger's theory was to consider the person in need of help as an expert in oneself, and the therapist's role to promote the patients self-awareness (Rogers, 1951, Rogers, 1961).

Michael Balint (1896-1970) highlighted the concept that the patient should be seen as the centre of the organisation of care and that every patient is a unique human being. He suggested to take into account the whole person by using psychotherapeutic tools to establish a diagnosis and had the ambition to renew the work of general practitioners from being illness-oriented to being more patient-centred (Balint, 1964, Balint, 1969).

The transfer of person-centredness into a caring context is attributable to the psychologist, Tom Kitwood (1937–1998), who used the concept when referring to desirable, person-centred care (PCC) that respects selfhood in persons with dementia (Kitwood, 1997). He opposed the contemporary attitude of treating people with dementia as objects with only physical needs to fulfil such as nutrition, elimination, respiration and circulation. In such view, the person behind the disease no longer existed and could even be termed as an empty shell or living dead, which negatively affected care (Hallberg, 2009). Kitwood stressed that the person still exists, has the need to be in a relationship, and use their abilities to experience well-being, but that this is hidden by the dementia and its symptoms (Kitwood, 1997). This view also comprises ethical requirements to meet the person with respect and to visualise and satisfy the needs of meaningfulness, activity, happiness and shared decision-making (Edvardsson *et al.*, 2008).

In PCC, the relationship is considered of equal importance as the health care task itself (Edvardsson and Nordvall, 2008). The concept of PCC is described as a core skill in nursing care (Svensk sjuksköterskeförening, 2010). In 2006, McCormack and McCance described a framework for person-centred nursing based on four constructs: prerequisites targeting the attributes of the nurse, environment focusing on the context in which care is delivered, person-centred processes (delivering care through a number of activities) and expected outcomes. To achieve person-centred outcomes, the required prerequisites and care environment need to be considered to provide effective care (McCormack and McCance, 2006).

From the perspective of a general practitioner, a comprehensive description of patient-centred care is provided by Stewart and colleagues, who present a model that identifies six interactive components: exploring both disease and the patients' illness experience, understanding the whole person, finding common ground, in-

corporating prevention and health promotion, enhancing the patient-physician relationship and being realistic about personal limitations and issues, such as the availability of time and resources (Stewart, 2003). Still, the literature on PCC mostly focuses on the physician's role and skills. Mead and Bower emphasised the importance of a therapeutic alliance and shared responsibility that should be obtained as the result of the relationship between the physician and the patient as a whole person. The patient's experience of the illness is as important as the disease and includes psychological and social perspectives (Mead and Bower, 2000). A prerequisite for PCC is to acquire knowledge about the patient, as a person, a capable human being with will, wishes, feelings and needs—to engage the person as an active partner in his/her care and treatment. To focus on the relational aspect, the patient as a person rather than the disease alone, implies that the person's view of his/her life situation and health is at the centre (Ekman *et al.*, 2011). A person-centred approach is a specific form of care within the scope of health care sciences, consisting of an interdisciplinary and multi-professional approach that aims to facilitate health for people in different situations. In health care sciences, as well as in PCC, the focus is on the patient and relatives in their context and based on their experiences. A person-centred approach has an ontological and ethical point of departure and adds an enhanced view of the patient as a person and partner in health care (Ekman *et al.*, 2011, Ekman *et al.*, 2014, Kristensson Ugglå, 2014).

Today, the concept of PCC is internationally established, attracting followers in several countries, such as Great Britain, Australia, New Zealand, USA, Norway and Sweden. This is reflected in national guidelines and policy documents aimed to promote PCC (Institute of Medicine, 2001, Epping-Jordan *et al.*, 2004, Ahmad *et al.*, 2014)

Patients as persons

Although there seems to be some consensus on the meaning of PCC, a standard definition is lacking. Further, it is unclear whether researchers and health care professionals share the same understanding of PCC, which complicates its application in health care (Mead and Bower, 2000, Edvardsson *et al.*, 2008, Ahmad *et al.*, 2014). One complicating factor is the linguistic confusion between person-centred and patient-centred. The term patient is more focused on the disease and treatment where the patient is categorised into a group of people which have a need of care in common. This ignores the uniqueness that each person possesses; thus, the difference between patient and person is important to consider. A person is constant, the role as a patient is temporary. A person is more than just an individual because a person is part of a social context; a person is always in relation with others. This means that, in case of illness and disease, PCC also integrates the partner, family, relatives and friends because the event usually has an effect on them as well (Ekman *et al.*, 2011, Ekman *et al.*, 2014, Kristensson Ugglå, 2014). A central aspect of the Swedish Health and Medical Services Act (SFS 1982:763) is that patients should participate in their own care, which recently was further

emphasised by means of an increased influence for patients over their care (SFS 2014:821). According to a position paper from the Swedish national centre for PCC (Gothenburg Centre for Person-Centred Care [GPCC]), the basis for a person-centred approach (henceforth gPCC) is the patient's experience, situation and resources. This suggests a shift towards an approach where patients are considered partners in their care. The person's knowledge and experience and their understanding of their health and well-being are particularly emphasised by this approach. Health care professionals are experts in diseases and treatment at a generic level, whereas the person is an expert on how he/she perceives their body and how the disease and treatment affects their daily life. In this gPCC approach, the person's own experience is of equal importance to that of the medical perspective where the disease often is seen as a matter of objective knowledge (Ekman *et al.*, 2011).

The GPCC definition is based on philosophical underpinnings. It assumes that persons have capacities and abilities by virtue of being human beings. The French philosopher Paul Ricoeur (1913-2005) describes his understanding of a human being as "homo capax" (the capable human). Ricoeur distinguishes between two fundamental aspects of the self, *idem* (what) and *ipse* (who) (Ricoeur, 1992). What a person is could be described by lining up several factors, such as the internal organs in the body, processes and chemical substances (Smith, 2010). For example in health care, it is common to line up several factors resulting from objective measures, tests and examinations. No matter how extensive or detailed this list becomes, it will only add more data onto what a person is rather than shed light on who a person is. Adding more *idem* (what) does not imply a greater understanding of *ipse* (who). It is the narrative that opens up the possibility of gaining access not just to what a person is but also who a person is (Ricoeur, 1992, Kristensson Uggla, 2014). The gPCC approach requires interactions with other people; thus openness to listening and learning from the person's narrative is crucial to know who a person is. Patients (often with the help of relatives) present themselves as persons by composing a patient narrative that includes their own experience of the illness. This initial presentation allows the beginning of the partnership between patients and health care professionals. Additionally, it allows the identification of personal resources that can be used as tools to empower patients to be more active in their care.

Person-centred dialogue

In PCC, shared information and shared decision-making are important to establish a partnership on which the relation is dependent. According to the philosopher Martin Buber (1878-1965), all actual life is meeting (Buber, 1994). To see each person by listening to the narrative, can be described with Buber's terms as an *I-thou relation*. It involves seeing the person as a subject on a mental and emotional level, which requires openness, presence, proximity and awareness. In contrast, an *I-it relation* is characterised by distance and seclusion, which may instead pro-

mote the view of the person as an object (Buber, 1994). In PCC, the person is invited to narrate, meaning that his/her thoughts, feelings and experiences are considered important. This approach allows to determine who a person is and development of the *I-thou* relationship.

The starting point of a person-centred dialogue is the narrative of the person. There are similarities with Carl Roger's client-centred therapy, which is based and defined on the experiences and thoughts of a person (Rogers, 1959). It has since contributed to the development of the different counselling approaches, such as motivational interviewing, a technique which focuses on what a person wants to change or achieve and how to find solutions to achieve those goals (Barth and Näsholm, 2006, Miller and Rollnick, 2012). The most important difference is that a person-centred dialogue is not a technique but an approach that emphasises the importance of listening to the narrative of the person to identify his/her viability and resources. There is someone (the person) who says something about something (narrative) to someone (the listener). The focus is on whom the person is which can be determined by listening carefully to the narrative (Ricoeur, 1976). A person-centred dialogue is transparent and performed with an open mind. If the narrative discloses *what* and/or *how* that involves changing a particular behaviour, then this creates conditions for subsequent goal-oriented counselling. Still, *who* needs to be identified in the first place, being the overarching aim in a person-centred dialogue. In the initial person-centred dialogue, it is not known nor given if the person wants to make any change. There is no agenda beforehand of the dialogue content. Starting with a blank page, the purpose is to identify the person's resources and abilities, as well as the obstacles to achieve their desired life. The objective may be to find the will to change as well as maintain the current situation. A precondition and challenge to accomplish a person-centred dialogue is the skill of listening to the narrative (only hearing is not enough) to create an atmosphere and relationship that promotes a self-reflective narrative. A person-centred dialogue sets great demands on listening and perceiving both the verbal and the non-verbal communication. Open ended questions, reflections and summaries contribute to the narrative (Fors, 2014).

Effects of person-centred care

The collective experience of PCC interventions is limited, in particular regarding those based on patient narrative in which the partnership between health care professionals and the patient is described as the core of the PCC intervention. A systematic review has evaluated clinical intervention studies based on these premises yielding eleven trials that fulfilled the inclusion criteria. In the majority of these studies, the PCC intervention was successful in several populations within the scope of diabetes, cardiovascular diseases, orthopaedics and neurology. The included studies differed regarding to methodology, setting, intervention, outcomes and effects, indicating a wide variation that complicates the generation of knowledge and establishing effective components (Olsson *et al.*, 2013).

Some of the studies refer to the gPCC approach that proposes three key steps of PCC to facilitate and safeguard the transition of PCC: 1) the patient's narrative is the first step in establishing a partnership; 2) shared decision-making strengthens the partnership; and 3) documentation in patient records not only sanctions the value of this information but also contributes to the continuity and transparency of the patient-health care professional partnership (Ekman *et al.*, 2011). In turn, operationalisation of this approach has showed positive effects in terms of shortening the hospital stay among patients with chronic heart failure (Ekman *et al.*, 2012) and hip-replacement (Olsson *et al.*, 2014). Hospital stay was also decreased among patients with hip-fracture (Olsson *et al.*, 2006) who also reported improved physical functioning, less pain and improved discharge planning (Olsson *et al.*, 2007). An improved discharge process has also been shown in patients with chronic heart failure (Ulin *et al.*, 2015). Additionally, less uncertainty in illness has been reported (Dudas *et al.*, 2013). The studies have also shown that gPCC is cost-effective (Olsson *et al.*, 2006, Hansson *et al.*, 2015).

Acute coronary syndrome

Coronary heart disease (CHD) is still the leading cause of death worldwide despite the fact that mortality rates from CHD have declined over the past decades in high income countries (Finegold *et al.*, 2013, Nichols *et al.*, 2013). This favourable declining trend, which is also observed in Sweden, is mainly attributed to a reduction in cardiovascular risk factors. However, it is also attributable to an improvement in secondary-prevention treatment (Björck *et al.*, 2009). Acute coronary syndrome (ACS) is a subset and a life-threatening form of CHD. The clinical signs of ACS are those of myocardial ischemia: ST-segment elevation myocardial infarction, non-ST segment elevation myocardial infarction and unstable angina pectoris. ACS occurs when a coronary artery is blocked by a blood clot, in most cases as a result of atherosclerosis (Overbaugh, 2009).

Chest pain is the most common reported symptom of ACS in both men and women. A variety of other symptoms, such as pain irradiating to the left arm and/or shoulder and neck and back; fatigue; sweating; nausea; and shortness of breath are also associated with impending ACS (Berg *et al.*, 2009, Coventry *et al.*, 2011, O'Donnell *et al.*, 2012). Especially among younger individuals, men are more likely to be affected of ACS than women. Among individuals aged <75 years in Sweden in 2013, nearly three out of four with at least one myocardial infarction event were men (The National Board of Health and Welfare, 2014). The literature is not fully consistent in whether there are any differences between men and women in terms of seeking prompt medical care, but most studies report that it is more common for women to delay in seeking care when experiencing ACS symptoms (Moser *et al.*, 2006, Isaksson *et al.*, 2008). Care and treatment differs between men and women. Women with myocardial infarction are prioritised differently than men prior to their admission to the coronary care unit (CCU) (Herlitz *et al.*, 2009).

Reports indicate that fewer women undergo invasive treatment, such as percutaneous coronary intervention and coronary artery bypass grafting (Herlitz *et al.*, 2009, Kuhn *et al.*, 2015).

The differences in diagnosis and treatment may be explained by the differences in the narrative of patients' illness and communication that may exist between men and women (Sjöström-Strand and Fridlund, 2008, O'Donnell *et al.*, 2012, Nielsen *et al.*, 2014). A person-centred approach incorporates being aware of and sensitive to issues regarding sex (biological) and gender (cultural and social expectations), which could increase the understanding of the patients' experience of the present illness (Björkman *et al.*, 2014). In fact, being a person always includes being sexed and gendered (Smith, 2010). Taking into account the patient's perspective, including values, beliefs and needs as well as his/her context, facilitates the development of an equalitarian partnership between patients and health care professionals and promotes health (McCormack and McCance, 2006).

Although patients with ACS will recover physically from the myocardial injury, it is common to report persistent symptoms, such as pain, anxiety and depression, which have a negative impact on the quality of life (Schweikert *et al.*, 2009). Depression and fatigue are seen as predictors of lower quality of life (Brink *et al.*, 2005). Return to work is complicated and adversely affected by a higher age, lower education, disease severity and comorbidity (SBU, 2003, Osler *et al.*, 2014). Patients with ACS also report feeling confused and uncertain about treatment and the severity of CHD (Roebuck *et al.*, 2001, Attebring *et al.*, 2005). In Sweden, the recommended period of sick-leave after hospitalisation for ACS is approximately 4 weeks (The National Board of Health and Welfare, 2007). The proportion of sick-leave as well as re-admission rates after a myocardial infarction have declined during recent years. Nevertheless, in 2013 approximately 30% were yet on part- or full-time sick leave up to 10 weeks after the cardiac event, and 15% were readmitted to the hospital during the following year (Swedeheart, 2013). Perceived work performance appears to be associated with age, physical function, perceived disease severity and symptom burden (Ellis *et al.*, 2005).

The value of secondary prevention programmes during ACS recovery is well documented (Clark *et al.*, 2007). However, the motivation to follow lifestyle recommendations (Twardella *et al.*, 2006, Andrikopoulos *et al.*, 2013) and cardiovascular medications (Jackevicius *et al.*, 2008, Calvert *et al.*, 2012) remains low. Additionally, the attendance to cardiac rehabilitation is low (Thompson and Clark, 2009). Further, the systematic follow-up of these patients is fragmented (Redfern *et al.*, 2014). One explanation for this setback is related to the beliefs of patients regarding their illness, which may differ compared with that of the health care professionals (Ekman *et al.*, 2011). Patient's beliefs have been found to influence their health outcomes and play an important role in whether they attend to cardiac rehabilitation (French *et al.*, 2006) and return to work after ACS (Petrie *et al.*, 2002).

RATIONALE

The recovery after ACS focuses on a change in behaviour of the patients based on current general recommendations associated with diagnosis rather than being attuned to each patient's preferences (Ekman *et al.*, 2011). It is rare that people attempt to perform a task if the outcome is expected to fail (Bandura, 1997b), and studies have confirmed that the probability to change a behaviour is weak without the belief in the ability to improve the health status by accomplishing a behaviour change (Lorig and Holman, 2003). Patients make decisions based on their beliefs and experiences, and they may believe that a course of action will lead to a desirable outcome, that is, guidance is pointless as long as patients have serious doubts as to whether they can succeed in performing the required activity (Bandura, 1977).

One important mechanism to improve health status is self-efficacy (Sullivan *et al.*, 1998, Lorig and Holman, 2003), which is defined as a person's conviction to successfully execute the behaviour necessary to produce desired outcomes (Bandura, 1977). Previous research has shown that self-efficacy can be improved by engaging patients in problem-solving and tailoring their skills to manage their health problems and their particular challenges (Lorig and Holman, 2003). However, the underlying factors to develop such engagement are lacking (Yehle and Plake, 2010).

Interventions need to target patients' beliefs in their ability to perform desired activities rather than just convincing them of the value of certain activities (Lau-Walker and Thompson, 2009). This point of departure is crucial in self-efficacy, and it is addressed by PCC, which stresses the importance of knowing the patient as a person with capacities and abilities to perform activities and achieve set goals (Bandura, 1997a, Ekman *et al.*, 2011). A PCC approach has been identified as a core component for sustainable high-quality health care (Institute of Medicine, 2001, Epping-Jordan *et al.*, 2004, Ahmad *et al.*, 2014) and as the starting point for collaborative and equalitarian care, and a health-professional-patient partnership that encourages and empowers patients to take part actively in finding solutions to their problems (Ekman *et al.*, 2011). Little is known about the relation between PCC and self-efficacy, but there is increasing evidence that patients, who are actively involved in their own care, and receive effective treatments, self-management support and regular follow-up in coordinated systems, report better outcomes and satisfaction with their care (Holman and Lorig, 2000, Tsai *et al.*, 2005).

A PCC approach focuses on the patient as a person rather than on the disease alone. It implies that there is an active partnership between the patient and health care professionals. This requires moderating and mediating variables in the PCC relationship. The value of the patient narrative and the partnership between the health care professional and the patient has only been evaluated to a limited extent (Olsson *et al.*, 2013). Additionally, an evaluation is missing on the effects of PCC in relation to self-efficacy throughout the continuum of care.

AIM

Overall aim

The overall aim of this thesis was to build an understanding of patients' prerequisites to collaborate as partners in their care after an event of acute coronary syndrome and to evaluate measures and the effects of a person-centred care intervention on self-efficacy and return to previous activity. Moreover, the goal was to identify if a person-centred approach can facilitate the care chain from hospital, outpatient and primary care for patients with acute coronary syndrome.

Specific aims

- Study I* To explore patients' experiences of acute coronary syndrome during their hospital stay.
- Study II* To validate a Swedish version of the cardiac self-efficacy scale by examining its psychometric properties.
- Study III* To evaluate if person-centred care can improve self-efficacy and facilitate return to work or prior activity level in patients after an event of acute coronary syndrome.
- Study IV* To evaluate if person-centred care can improve cardiac self-efficacy after hospitalisation for acute coronary syndrome.

METHODS

Design

In this thesis, a multi-method design was used by combining qualitative and quantitative methods. This design aims to form a comprehensive depiction of the study area (Morse, 2003). A qualitative method was used to generate meaning by in-depth analysis based on single cases, while quantitative methods made it possible to validate and to generalise the results on a statistical level. Qualitative and quantitative research methods complemented each other by creating varied knowledge (Polit and Beck, 2012). Study I was qualitative and Study II-IV were quantitative studies. The studies are presented in greater detail in Table 1.

Table 1. Research design

| Study | I | II | III | IV |
|-----------------|---|---------------------------------|---|--|
| Design | Interpretative | Correlational | Experimental Randomised controlled trial | Experimental Randomised controlled trial |
| Data collection | Narrative interviews | Questionnaire CSES | Composite of changes (GSES, work or activity level, worsening events) | Questionnaire CSES |
| Participants | Persons with ACS (n=12) | Persons with ACS (n=288) | Persons with ACS (n=199) | Persons with ACS (n=177) |
| Data analysis | Phenomenological hermeneutical method | Confirmatory factor analysis | Descriptive statistics, non-parametric statistics, logistic regression | Descriptive statistics, parametric statistics |

ACS=acute coronary syndrome; CSES=cardiac self-efficacy scale; GSES=general self-efficacy scale

Participants and setting

Study I

In the first study, patients aged <75 years, who were admitted to two designated coronary care units in Sweden with a preliminary diagnosis of ACS according to the International Classification of Diseases Version 10 (ICD 10), I20.0, I20.9 (unstable angina pectoris) and I21 (myocardial infarction), were screened. A strategic sampling method was applied to generate a study group including both men and women of various ages. The inclusion criteria were as follows: (a) men and women aged <75 years; (b) diagnosis of ACS or suspected ACS (working diagnosis) established on the basis of symptoms and electrocardiographic changes and/or confirmed by abnormal elevation of cardiac enzyme levels; (c) at least referred

for coronary angiography; (d) hospitalised in CCU and physical and mentally able to participate in an interview during hospital stay. All patients asked (n=12), five women and seven men aged 45–72 years (median age 62.0 years), chose to participate. The majority were married and employed, and had a length of hospital stay ranging between 4 and 14 days. All were diagnosed with ACS as their main diagnosis at discharge; seven had myocardial infarction (I.21 [ICD 10]) and five patients, unstable angina pectoris (I.20.0 [ICD 10]).

Study II

The participants in Study II were derived from a cohort consisting of two subsamples of patients ≤ 75 years who were admitted to the hospital for ACS in either of two hospitals in the western Sweden. Between March 2011 and March 2012, the first subsample (a) of 140 patients (32 women and 108 men, with a mean age of 62.8 years) was included from a study, initiated at a CCU, at a rural hospital concerning fatigue after myocardial infarction. The second subsample (b) was recruited from a randomised controlled trial (RCT) (Study III) that examined the effects of PCC, which started from two CCUs at a university hospital. Subsample (b) in Study II were represented by patients who were enrolled in the RCT (Study III) between June 2011 and May 2013 and comprised 148 patients (40 women and 108 men, with a mean age of 61.6 years) from both the intervention and control group. In both subsamples, patients were excluded if they had other severe diseases (e.g., advanced cancer), cognitive disability or current abuse of alcohol or drugs. These two subsamples provided an overall cohort of 288 patients (72 women and 216 men, with a mean age of 62.2 years) (Table 2).

Table 2. Characteristics of the study group

| | All n=288 | Subsample (a) n=140 | Subsample (b) n=148 |
|--|----------------------|--------------------------------|--------------------------------|
| <i>Characteristics</i> | | | |
| Myocardial infarction, n (%) | 237 (82.3) | 140 (100) | 97 (65.5) |
| Unstable angina pectoris, n (%) | 51 (17.7) | - | 51 (34.5) |
| Gender, female, n (%) | 72 (25) | 32 (22.9) | 40 (27) |
| Age at inclusion, mean (SD) | 62.2 (± 8.6) | 62.8 (± 8) | 61.6 (± 9.2) |
| <i>Highest Education Level</i> | | | |
| Elementary school (n) | 98 | 68 | 30 |
| High school (n) | 105 | 48 | 57 |
| University (n) | 85 | 24 | 61 |
| <i>Medical history</i> | | | |
| Myocardial infarction (n) | 53 | 14 | 39 |
| <i>Acute treatment at hospital</i> | | | |
| Percutaneous coronary intervention (n) | 151 | 49 | 102 |
| Coronary artery bypass grafting (n) | 10 | 5 | 5 |

Study III-IV

The study was conducted at Sahlgrenska University Hospital (3 CCUs and 2 outpatient clinics), the Angered local hospital (outpatient clinic) and all public primary care centres in Gothenburg (n=43). An original invitation was sent out to all public primary care centres. Five centres geographically disseminated over the Gothenburg region participated voluntarily as intervention primary care centres. Each of these centres consisted of designated gPCC professionals (physician and registered nurse [RN]) who applied a gPCC approach and worked with the patients in a gPCC team. The other staff at those centres and the other primary care centres applied usual care. This means that patients in the control group were assigned to their usual primary care centre, while those randomised to the gPCC intervention may have had to visit another primary care centre than they previously were listed in during the study period (12 months).

Inclusion criteria were as follows: men and women aged <75 years who were hospitalised for ACS, with a diagnosis of acute myocardial infarction (I21 [ICD 10]) or unstable angina pectoris (I20.0 or I20.9 [ICD 10]). Exclusion criteria were as follows: ≥75 years of age, currently listed at a private primary care centre or at a primary care centre in another region, no permanent address, planned heart surgery such as coronary artery bypass grafting, cognitive impairment, alcohol and/or drug abuse, survival expectancy less than one year or participating in a conflicting study. All eligible patients willing to participate were included in the study within a 72-hour period after hospital admission. After randomisation, additional exclusion criteria were misdiagnosed as ACS and anticipated extended hospital stay >14 days (e.g., coronary artery bypass grafting).

Data collection and procedure

Study I

Individual, tape-recorded narrative interviews were conducted (mean time for the sessions was 25 minutes) and transcribed verbatim. All interviews were performed during hospitalisation in the patients' rooms or in a private room nearby the CCU. The aim of the interview was explained to the interviewees, who were encouraged to speak freely about their current ACS illness experience. The opening question was: "Could you please tell me about what happened and how you felt when you were admitted to the hospital?" The interviewer listened to the interviewees and their narrative, and to obtain as comprehensive responses as possible asked consecutive and supplementary questions such as: "Can you please tell me more about that?", "Can you give me an example?" or "How did you feel?" The interviews continued until the interviewer considered the research question to be fully answered.

Study II

The original version of the cardiac self-efficacy scale (CSES) consists of 13 items

of which eight items represent the control symptoms dimension and five items represent the maintain functioning dimension (Sullivan *et al.*, 1998). To measure cardiac self-efficacy (CSE) in a Swedish population, the CSES was translated from English to Swedish. The forward translation into Swedish was carried out independently by two Swedish speaking researchers within the research field. In the next step, a researcher who is a native English speaker performed the backward translation into English, and all arising discrepancies were resolved. This resulted in a preliminary Swedish version based on synthesis from these two translations. To pre-test the instrument, a pilot study was carried out on approximately 10 to 15 respondents in the target population who found the questionnaire easy to understand and respond (World Health Organization, Fayers and Machin, 2000). The final Swedish version of the CSE scale (S-CSES) (Appendix 1) was sent by post to the participants two months after their ACS event in order to complete the S-CSES questionnaire. Subsample (a) also answered the general coping questionnaire including the fatalism scale and subsample (b) also answered the general self-efficacy scale (GSES).

Measurements

Cardiac self-efficacy. The CSES was originally developed by Sullivan *et al.* to examine the role of specific CSE in managing the challenges posed by coronary disease in terms of control symptoms and maintain physical functioning (Sullivan *et al.*, 1998). The CSES consists of 13 items in which patients are asked to rate their confidence to know or act on each of the items on a 5-level Likert scale (0=not at all, 1=somewhat confident, 2=moderately confident, 3=very confident, 4=completely confident).

General self-efficacy. The GSES is a 10-item questionnaire that refers to the global confidence in a person's belief in the ability to successfully respond to challenges across a wide range of situations, for example, dealing efficiently with unexpected events, handling unforeseen situations, and finding solutions to problems. Respondents are asked to rate their self-confidence on a 4-point scale (1=not at all true, 2=hardly true, 3=moderately true, 4=exactly true). The total score ranges from 10–40 (Schwarzer R and Jerusalem M, 1995) (Appendix 2).

Fatalism. The fatalism scale is one dimension in the general coping questionnaire that consists of four items with responses on a 6-point scale (from I always think or act like this to I never think or act like this) reflecting a person's beliefs that their outcome depends on fate, luck or others and that you do not control it yourself (Brink *et al.*, 2009).

Study III-IV

Patients hospitalised with ACS were randomised to usual care (control) or gPCC (intervention), after providing written informed consent. The randomisation was conducted using a block design and consisted of two stratification steps performed at two different hospital sites (site I and II) within the Sahlgrenska University Hospital, Gothenburg, Sweden. The first stratification was per hospital

site and the second stratification was performed at each site by activity level: 1) working group (employed, studying or in search of work) or 2) retired or permanent full-time sick leave. The randomisation was performed via opaque, closed and numbered envelopes for each stratum to be used in an ordered way. Follow-up questionnaires concerning GSE (Schwarzer R and Jerusalem M, 1995) and CSE (Sullivan *et al.*, 1998) were filled in at each hospital and then sent out to all patients in both groups at four weeks, eight weeks and six months after discharge. A questionnaire about physical activity level was filled in by all participants during the hospital stay and again at 6 months after discharge (Saltin and Grimby, 1968).

Control group

Patients enrolled in the control group were managed by usual care procedures (The National Board of Health and Welfare, 2008/2011), including two standard individual follow-up visits at the out-patient clinic at each hospital, one with an RN (about 2-3 weeks after discharge from hospital) and one with a cardiologist (approximately 6 weeks after discharge from hospital). If in the patients were in a stable medical state, they were followed up at their ordinary primary care centre after approximately 8 weeks after discharge from the hospital where the medication and rehabilitation was planned by the primary care physician and, where appropriate, with other professionals (i.e., RN or physiotherapist). Usual care also meant that medical referrals and discharge notes were shared by health care professionals at the units but not necessarily with the patients.

Intervention group

The intervention was provided by a group of health care professionals at hospital, outpatient and primary care levels who were specially prepared through lectures, seminars and workshops on to the application of the gPCC intervention. The staff collaborated in designated gPCC teams (patient, physician and RN) along the chain of health care. During the study period, four follow-up educational meetings, of 3 hours each, were organised regularly to share experiences and maintain a continuous application of gPCC. The intervention staff was mainly stable, except for one gPCC team at the primary care level where both the physician and the RN were replaced during the study period because of altered duty. Patients in the intervention group received the gPCC approach (initiating, working and safeguarding the partnership) (Ekman *et al.*, 2011), which emphasised the patient as a partner at three health care levels:

a) Hospital stay

Admission. A structured patient narrative was collected by an RN at admission to the hospital (within 24 hours after randomisation). This was the starting point of the intervention to *initiate the partnership* and the basis for the preparation of a personal health plan (gPCC plan). The gPCC plan consisted of a description of the goals and the actions needed to accomplish them; personal resources; assigned health care professionals; location, time and date of appointments; and follow-up objectives. The gPCC plan was developed by the patient together with health care professionals

to define opportunities and barriers during recovery after ACS. The focus was on each person's resources to achieve set goals during the recovery process. For example, the specific activities the patient felt confident enough to take up and even perform extendedly (work or leisure activities) were identified. The condensed narrative was discussed in a meeting between the patient, RN and physician and then compiled in the gPCC plan after patient's approval.

Inpatient care. To work with the partnership, an appointment for shared decision-making was set between the patient, RN and physician within 48 hours after randomisation to consider and jointly agree on and sign the gPCC plan. Further discussions of the patient's medical status and a presumed day for discharge were also recorded in the gPCC plan. Additionally, patients rated their symptoms during the development of the gPCC plan, which were then transferred into the gPCC plan. Symptoms were followed every 48-hour period during the hospital stay and followed up by health care professionals. The gPCC plan was reviewed and revised when necessary.

Discharge procedure. At discharge from the hospital, a summarised version of the gPCC plan was enclosed in a referral in addition to the discharge notes and medical referrals to the outpatient clinic and the primary care centre. The referral form was based on the personal gPCC plan that had been previously formulated together with the patient and reflected the patient's view on continued care to achieve future goals and improve health. It was sent along with all the patient documents (e.g., medical and nursing referrals) to the gPCC teams at the outpatient clinic and the primary care centre, and it was shared by health care professionals and the patient. The gPCC plan was documented in the patient's record to *safeguard the partnership* and was accessible for both the patient and the staff throughout continuum of care.

b) Outpatient visit

At approximately four weeks after discharge from the hospital, the patient met the physician and an RN in a team visit at the outpatient clinic. To *maintain the partnership*, the visit started by following up on the gPCC plan, which served as the basis for the discussion of the overall condition and possibly involved revisions of the plan. If the gPCC team decided that the patient's medical condition was stable, the patient was referred to one of the five designated primary care centres.

c) Primary care centre visit

A member of the gPCC team at the primary care centre contacted the patients directly after the hospital discharge to confirm their assignment to the team, to set a date for the first visit and to inform them that they could contact the team if needed before the visit. After about eight weeks, the

patient met a physician and an RN in a team visit at the dedicated primary care centre. To *maintain the partnership*, the goals in the gPCC plan were assessed and modified when required. For example, goals could be divided into several minor goals to achieve them stepwise, or a new goal orientation could be set. Resources within the person and support within the patient's network or among other health care professionals were identified to contribute to the realisation of set goals. Symptoms were followed up, for example if sleep disorders and/or anxiety were reported during hospital stay, management strategies were discussed during the visit. The patient was encouraged to discuss the gPCC plan with the team throughout study period, and additional gPCC team visits were scheduled (but not necessarily) if suggested by either the patient or the health care professional (Figure 1).

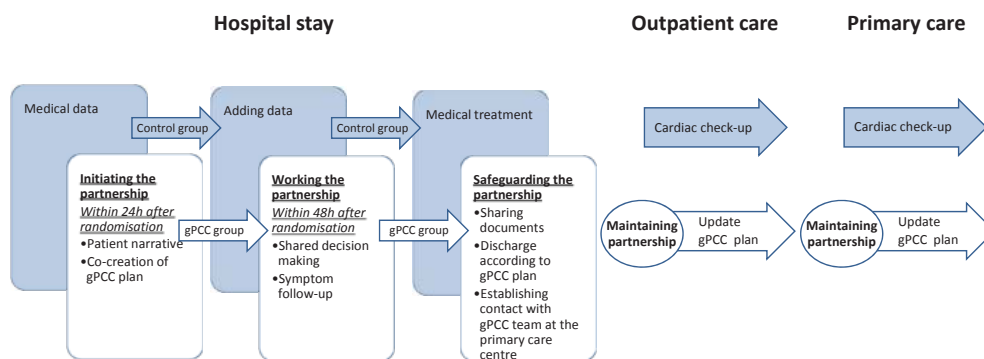


Figure 1. The care chain for control and intervention in Study III-IV. Both groups received the content in the blue area (treatment as usual). The Gothenburg Person Centred Care (gPCC) components (white area) were added to treatment as usual in the intervention group.

Data analysis

Phenomenological hermeneutical analysis (Study I)

Ricoeur stated that phenomenology and hermeneutics are mutually related in the sense that phenomenology has an intermediate nature that hermeneutics reveals and hermeneutics can itself not be constituted without the phenomenological condition (Ricoeur, 1981). Humans can talk about their lives and express their feelings, thoughts and actions and their perceptions and experiences through language. This lived experience is always personal, but its meaning can be conveyed to others through narratives. By interpreting these narratives, it is possible to clarify the meaning and then pass it on to others (Ricoeur, 1976). The interpretation of the 12 interviews performed in this study implied three interrelated phases: *naïve reading*, *structural analysis* and *comprehensive understanding* (Lindseth and Norberg, 2004). During naïve reading, the whole text was read repeatedly to get an immediate and overall impression of the text. The understanding achieved

by naive reading led to the structural analysis in which each section was read carefully. Then, meaning units were identified and excerpted from the text. These units were critically reviewed in relation to the naive understanding. Similar patterns were then determined and sub-themes created to formulate the themes. In the final step, the whole text was re-read and critically interpreted, including pre-understanding, naive reading and structural analyses, to formulate a comprehensive understanding of the narrative (Lindseth and Norberg, 2004).

Confirmatory factor analysis (Study II)

The S-CSES was fulfilled by a sample of 288 respondents and the construct validity was psychometrically evaluated by using confirmatory factor analysis, Mplus version 5 (Muthén and Muthén, (1998-2007)). Goodness of fit was estimated by performing the following tests: χ^2 , χ^2/df (should be below 2–3), the comparative fit index (CFI), the standardised root mean square residual (SRMR) and the root mean square error of approximation (RMSEA). CFI scores are in the range of 0–1. Goodness-of-fit values over 0.9 are considered to be acceptable. Values over 0.95 are considered excellent. A model that exhibits an acceptable fit should have a RMSEA below 0.08 to be acceptable, whereas to be good it should be below 0.05. A SRMR value is considered as good fit if the value is below 0.08 (Brown, 2006). Convergent and discriminant validity were tested using Pearson's correlation coefficient. To examine convergent validity, the GSES (Schwarzer R and Jerusalem M, 1995) was used. To test the discriminant validity, the fatalism scale in the general coping questionnaire was used (Brink *et al.*, 2009). The GSES was picked to test convergent validity as it has the same underpinnings as the S-CSES in terms of self-efficacy. Therefore, it is likely that the scores of patients will trend toward a similar direction with these two scales. To test discriminant validity, the fatalism scale was chosen because theoretical reasoning, suggested the likelihood that people with higher scores on the fatalism scale (e.g., believing that one cannot control outcomes oneself) will have lower scores on the S-CSES (e.g., believing that one's ability to control chest pain is low).

Statistical analysis (Study III)

Ninety-one patients were required in each group (comparison and intervention) to achieve an 80% power based on an alpha-error of 0.05 for detecting an improvement rate in the composite score from 20% in the control group to 40% in the intervention group. To have some margin for withdrawal, at least 110 patients were included in each group. Descriptive statistics were used to characterise the study groups. Between group differences were tested using the Fisher's exact test for dichotomous variables and the Mann-Whitney U test for continuous variables. Logistic regression was used to calculate the odds ratio with 95% confidence interval (CI). All statistical tests were two-sided with a significant level of $P \leq 0.05$. The data were analysed using SPSS version 22 (IBM Corp, 2013).

The primary endpoint was a composite of changes in the GSES, re-hospitalisation or death and return to work or previous activity level. Previous activity level was

measured by the Saltin Grimby Physical Activity Level Scale, which is a validated self-reported measure of physical activity on a 4-point scale (sedentary, moderate, demanding or strenuous) (Saltin and Grimby, 1968) that has been shown to correlate with cardiovascular risk factors (Rodjer *et al.*, 2012).

The composite score was used to assess patients' situation as improved, unchanged or worsened after 6 months. It was considered improved if the patient returned to work or previous activity level and the self-efficacy increased by ≥ 5 units; deteriorated when self-efficacy declined by ≥ 5 units or the patient was re-admitted for unexpected cardiovascular event or death; unchanged if the patient's condition neither improved nor worsened. Patients were dichotomised into improved versus deteriorated/unchanged.

Statistical analysis (Study IV)

In Study IV, descriptive statistics were used to characterise the study groups. Categorical variables were analysed with Pearson's chi-squared test and Fisher's exact test and described with frequencies and percentages. Continuous variables were described using means, standard deviations (SD) and medians and comparisons between groups were performed using t-test with 95% CI. All statistical tests were two-sided with a significance level of $P \leq 0.05$. Data were analysed using SPSS version 22 (IBM Corp, 2013).

Standardised response means (SRM) were calculated to estimate the clinical significance of the magnitude of between-group changes in the S-CSES scores. SRM was calculated as the difference between mean change scores divided by the pooled SD of change in the two groups. SRM magnitudes were interpreted against criteria suggested by Cohen: trivial (0 to <0.2), small (≥ 0.2 to <0.5), moderate (≥ 0.5 to <0.8) and large (≥ 0.8) (Cohen, 1969). Small SRMs were considered to correspond to minimum clinically important differences (Hays and Woolley, 2000).

Intention-to-treat analysis included patients with an ACS diagnosis, who were willing to participate and did not meet any exclusion criteria. The per-protocol analysis excluded patients from the analysis who were assigned to the gPCC team where the staffs were replaced during the study period. Assessment of change in the S-CSES between the two study groups was evaluated at baseline (4 weeks after discharge), 8 weeks and 6 months.

ETHICAL CONSIDERATIONS

All studies within the thesis were approved by the Regional Ethical Review Board in Gothenburg, Sweden (Study I, III and IV D No. 275-11; Study II D No. 720-10 and D No. 275-11) and conformed to the principles outlined in the Helsinki Declaration (World Medical Association, 2013). In all studies (Study I-IV), patients were asked to participate when they were considered as clinically stable. In Study I, interviewees gave their informed consent to participate, and their responses were treated with full confidentiality. The interviewees were informed that if they felt that some issues were too sensitive to discuss, they could withdraw from the study at any time without giving reasons.

In Study II-IV, each participant answered questionnaires that could be experienced as personal and possibly awaken sensitive thoughts. If they did not wish to continue responding to the questions, participants were free to interrupt at any time without giving reasons as well as contact the responsible research staff if needed. In all studies (Study I-IV), participants were offered to consult with a counsellor if required. In Study II-IV, interpreters were used when needed to translate the questionnaires into the participant's native tongue. Participants gave their written informed consent to participate, and their data were stored in a data record with authorised access only. When processing the data the participant's names and social security number were replaced with a unique identifier code. Only research staff of the study had access to the key code; thus, no individual could be identified when processing and presenting data from the studies.

RESULTS

A call for person-centred care (Study I)

Experiencing ACS was interpreted as *awareness that life is lived forwards and understood backwards*. A comprehensive overview of the themes and sub-themes are illustrated in Table 3.

Table 3. Main theme, themes and sub-themes

| Awareness that life is lived forwards and understood backwards | |
|--|--|
| Struggling to manage the acute overwhelming phase | Striving to obtain a sense of inner security |
| Onset of life-threatening symptoms | Searching for and processing the cause and its explanation |
| Fear and anxiety | Maintaining a personal explanation |
| Being taken by surprise | Dealing with concern and uncertainty |
| Experiencing life as a hazardous adventure | Having a readiness to negotiate with life-pattern activities |

When struggling to manage the acute overwhelming phase, patients reported a variety of symptoms. The most common was chest pain; other symptoms such as breathlessness, sweating, fatigue and air hunger were also mentioned. Symptom onset could occur suddenly or gradually, and when perceived as life-threatening, they induced panic, fear and anxiety of examinations and surgeries, as well as fear of not surviving the ACS event. Patients referred to their symptoms of other less serious conditions, and for most of them, the onset of the disease was unexpected and caused concern and uncertainty during the hospital stay. It became clear from the interviews that they were made aware of the heart's vital function and life's unpredictability.

The narrative text disclosed that patients affected by ACS experience life as hazardous, which seems to imply a process by which they were striving to obtain a sense of inner security. To manage these feelings, they spent a lot of time and energy considering the cause of the disease and its explanation. Heredity and lifestyle factors were considered. For some of the patients, the onset of the ACS event seemed unfair since they could not find any explanation in terms of risk factors. They were eager to find an explanation and formulated own perspectives trying to clarify the cause and its effects. For some patients, it was important to come up with their own explanation rather than being informed by health care professionals. A few patients even inclined more to their own explanation, rather than the one given by health care professionals to elucidate the cause of their disease. Patients reported an overall feeling of concern and uncertainty, both in relation to the initial stages of the disease and also for the recovery period. Another finding was that they were still in position to negotiate with life-pattern activities such as return to work and start physical exercise regimens.

Overall, they almost immediately started to reflect on the causes and effects of their disease. This suggests that despite the acute situation, they were eager to consider the cause of the onset as early as during the hospitalisation. The patients constructed individual models that served as an explanation for being affected by the disease and that at the same time, functioned as support to prepare them to manage their future health conditions. Taking into account each patient's perspective can strengthen the collaboration between patients and health care professionals. However, these findings urged subsequent studies related to this thesis to target how an intervention based on a PCC approach could be adapted, performed and evaluated in order to improve health outcomes after an event of ACS.

Validation of the cardiac self-efficacy scale (Study II)

To evaluate PCC, valid and reliable measures are required, especially instruments that are based on theoretical concepts related to PCC. Therefore, in Study II, the S-CSES was psychometrically evaluated. The analysis showed that the S-CSES was found to be a valid and reliable measure to evaluate specific CSE in relation to ACS. However, some changes were suggested, in comparison with the original CSES.

The analysis showed that the S-CSES comprised 12 items distributed on three dimensions (control symptoms, control illness and maintain functioning) in contrast to the original CSES, which consists of two dimensions and a total of 13 items. Modification indices and face validity confirmed that the first four items in the scale had to be considered as an independent dimension (control symptoms) and that the following three items corresponded to a new dimension (control illness). Item 8 in the original CSES (belonging to the control symptoms dimension) also interacted with the maintain functioning dimension. In particular, this item correlated positively with the last item. Thus, it was considered unreliable and was consequently removed from the S-CSES. A covariance was also detected between items 3 and 4, which may be a result of the wording of these two items. To condense, a three-factor model, excluding item 8, and taking into account a covariance between items 3 and 4 resulted in an excellent CFI score (0.965), a good SRMR (0.047) and an acceptable (slightly above to be considered as be of good fit) RMSEA (0.058) (Table 4).

Since the covariance among the three factors was relatively high, a higher order model was specified and found to reflect one global latent variable (global CSE) based on a total summary score of the S-CSES. Cronbach's alpha calculation for the 12 items resulted in excellent reliability (0.89), and the convergent and discriminant validity showed the expected relations; that is, the S-CSES correlated positively with the GSES and negatively with the fatalism scale in the general coping questionnaire (Table 5). The S-CSES was used in Study IV in this thesis to evaluate the effects of a PCC intervention after ACS.

Table 4. Goodness of fit indices for the models

| Model | χ^2 value | Df | RMSEA | SRMR | CFI |
|--|----------------|----|-------|-------|-------|
| Three-factor model | 240.380 | 62 | 0.100 | 0.084 | 0.878 |
| Three-factor model minus item 8 | 187.759 | 51 | 0.096 | 0.071 | 0.901 |
| Three-factor model minus item 8 and covariance between the residuals of item 3 and 4 | 97.972 | 50 | 0.058 | 0.047 | 0.965 |

CFI=comparative fit index; Df=degrees of freedom; RMSEA=root mean square error of approximation; SRMR=standardised root mean square residual.

Table 5. Correlations between the dimensions in the Swedish version of the CSES and other measured variables (convergent and discriminant validity)

| | GSES correlation | Fatalism correlation |
|------------------------------|------------------|----------------------|
| Control symptoms | +0.450 (p=0.000) | -0.284 (p=0.001) |
| Control illness | +0.285 (p=0.000) | -0.122 (p=0.156) |
| Maintain functioning | +0.513 (p=0.000) | -0.424 (p=0.000) |
| Global cardiac self-efficacy | +0.602 (p=0.000) | -0.377 (p=0.000) |

GSES=general self-efficacy scale; Fatalism=fatalism scale in the general coping questionnaire

Effects of person-centred care (Study III-IV)

For study enrolment in the RCT, 3982 patients were screened between June 2011 and February 2014, of which 445 met the eligibility criteria. Of these, 193 declined to participate and 252 were randomised into the trial. After randomisation, 53 patients were excluded because they were not diagnosed with ACS at discharge (n=22), assessed for coronary artery bypass grafting (n=13), had a hospital stay >14 days (n=10) or withdrew from the study (n=8). Finally, 199 patients (94 in the intervention group and 105 in the control group) <75 years participated and were assessed (Study III). Participant demographics are shown in Table 6. In Study IV, 22 more patients were excluded (12 control, 10 intervention) since they did not respond to the S-CSES at baseline, yielding a total of 177 participants. No significant difference concerning any baseline characteristics was observed in Study III-IV.

Composite score (Study III)

The results in Study III and IV derive from an interventional study with an RCT design that evaluated PCC at three health care levels (hospital, outpatient and primary care levels) after being affected by ACS. The primary endpoint was a composite of changes in GSES, return to work or prior activity level and re-admission to the hospital for unexpected cardiovascular events or death. At 6 months, the composite score showed that a higher number of participants in the gPCC group improved in comparison with the usual care group (22.3%, n=21 versus 9.5%, n=10; Odds ratio=2.7, 95% CI: 1.2-6.2; P=0.015) (Table 7).

Table 6. Baseline characteristics

| | Control (n=105) | Intervention (n=94) |
|--|----------------------------|--------------------------------|
| Age (mean(SD)) | 61.3(8.9) | 60.5(9.3) |
| Female (%) | 32(30.5) | 23(24.5) |
| BMI (mean(SD)) | 28.6(5.0) | 28.5(4.6) |
| General Self-Efficacy Score (mean(SD)) | 30.3(5.6) | 29.5(6.2) |
| Length of hospital stay (mean(SD)) | 4.34(2.7) | 4.36(2.3) |
| Activity (%) | | |
| Work | 60(57.1) | 54(57.4) |
| Retired | 45(42.9) | 40(42.6) |
| Indexed events (%) | | |
| STEMI | 24(22.9) | 24(25.5) |
| NSTEMI | 51(48.6) | 38(40.4) |
| Unstable angina | 30(28.5) | 32(34.0) |
| PCI | 83(79.0) | 67(71.2) |
| Medical history (%) | | |
| Previous MI | 25(23.8) | 23(24.5) |
| Previous angina | 34(32.4) | 28(29.8) |
| Previous PCI | 29(27.6) | 26(27.7) |
| Hypertension | 58(55.8) | 50(53.2) |
| CABG | 14(13.3) | 13(13.8) |
| Stroke | 4(3.8) | 5(5.3) |
| Diabetes | 27(25.7) | 23(24.5) |
| ICD | 2(1.9) | 0(0) |
| Pacemaker | 2(1.9) | 1(1.1) |
| Current or previous smoker (%) | 61(58.1) | 57(60.6) |

BMI=body mass index; STEMI=ST elevation myocardial infarction; NSTEMI=non ST elevation myocardial infarction; MI=myocardial infarction; PCI=percutaneous coronary intervention; CABG=coronary artery bypass grafting; ICD=implantable cardioverter defibrillator.

Table 7. Primary endpoint

| | Control n=105 6 Months | Intervention n=94 6 Months | |
|-------------------|---------------------------------------|---|-------------------|
| Composite score | | | P-value 0.018* |
| Improved n(%) | 10(9.5) | 21(22.3) | |
| Unchanged n(%) | 65(61.9) | 47(50.0) | |
| Deteriorated n(%) | 30(28.6) | 26(27.7) | |

*Composite score dichotomised into improved versus deteriorated/unchanged.

Splitting the composite score into each component separately showed that the GSES improved significantly in the gPCC group ($P=0.026$). Additionally, in the gPCC group, 48.3% ($n=42$) compared with 31.6% ($n=31$) in the usual care group significantly improved more than 1.5 units (mean difference between groups) in the GSES ($P=0.024$) (Figure 2). The other components were similar between groups; 18 worsening events (4 deaths, 14 re-admitted) occurred in the gPCC group versus 14 (2 deaths, 14 re-admitted) in the usual care group. At 6 months, 88.5% ($n=77$) of the gPCC group versus 90.8% ($n=89$) in the control group had returned to work or prior activity level.

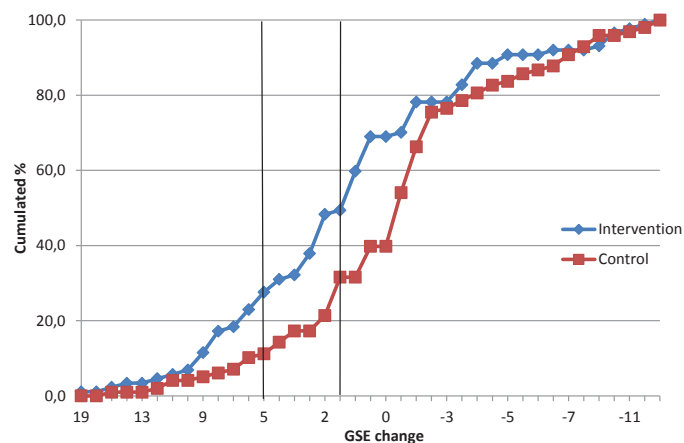


Figure 2. Cumulative response curves showing individual change in the general self-efficacy scale (GSES) from baseline to 6 months for the two treatment groups. The thresholds for clinical important difference (5 points) and the mean difference in the GSES score between groups (1.5 points) are illustrated by vertical lines.

Cardiac self-efficacy (Study IV)

A secondary endpoint of the RCT study was to evaluate the effects of the gPCC intervention on the S-CSES (validated in a Swedish population with ACS in Study II), which was the objective with Study IV in this thesis. At the 4-week follow-up, the gPCC group reported improved scores in the control symptoms dimension, indicating higher CSE in both the intention-to-treat [mean change (SD)=0.81 (3.5)] and the per-protocol analyses [mean change (SD)=0.92 (3.5)], while the control group reported worsening scores [mean change (SD)=-0.20 (3.0)]. The difference between groups was statistically significant in the intention-to-treat ($P=0.049$) and per-protocol analyses ($P=0.036$) (Table 8). SRMs were small in the intention-to-treat analysis ($SRM_{ITT}=0.31$; 95% CI=0.05–1.97) as well as in the per-protocol analysis ($SRM_{ITT}=0.34$; 95% CI=0.16–2.08). Regarding the global CSE, the illness and maintaining function dimensions, there were no significant between-group differences in change scores at the 4-week follow-up. At the 6-month follow-up, there were no differences in change scores between groups in any of the variables in the S-CSES, either in the intention-to-treat or per-protocol analyses.

Table 8. Between group comparisons of the Swedish Cardiac Self-Efficacy Scale (S-CSES) global and dimension change scores at 1-month and 6-month follow ups. Results are shown for both intention-to-treat and per-protocol analyses

| S-CSES | Usual care group n=93 | | | gPCC group n=84 (ITT) | | | P-value | |
|---|-----------------------|-------------------------|-------------------------|-----------------------|-------------------------|-------------------------|---|--|
| | Baseline* | Δ baseline - 1-month | Δ baseline - 6-month | Baseline* | Δ baseline - 1-month | Δ baseline - 6-month | Difference between groups (baseline → 1-month follow-up) | Difference between groups (baseline → 6 months) |
| Control symptoms dimension; Mean (SD) | 9.9 (3.8) (n=93) | -0.20 (3.0) (n=82) | 0.18 (3.3) (n=87) | 9.6 (4.0) (n=84) | 0.81 (3.5) (n=81) | 0.69 (3.9) (n=77) | 0.049 | 0.366 |
| Control illness dimension; Mean (SD) | 9.2 (2.0) (n=93) | -0.08 (1.6) (n=81) | -0.34 (2.0) (n=87) | 9.2 (2.0) (n=84) | 0.16 (1.8) (n=81) | -0.10 (2.3) (n=77) | 0.378 | 0.454 |
| Maintain function dimension; Mean (SD) | 13.8 (4.7) (n=93) | -0.01 (2.7) (n=81) | -0.08 (3.4) (n=87) | 13.3 (5.1) (n=84) | -0.17 (2.9) (n=81) | -0.26 (3.1) (n=77) | 0.726 | 0.724 |
| Global cardiac self-efficacy; Mean (SD) | 32.9 (8.4) (n=93) | -0.11 (5.4) (n=80) | -0.23 (6.8) (n=87) | 32.1 (9.2) (n=84) | 0.82 (5.9) (n=81) | 0.37 (6.9) (n=76) | 0.299 | 0.577 |
| S-CSES | Usual care group n=93 | | | gPCC group n=72 (PP) | | | P-value | |
| | Baseline* | Δ baseline - 1-month | Δ baseline - 6-month | Baseline* | Δ baseline - 1-month | Δ baseline - 6-month | Difference between groups (baseline → 1-month follow-up) | Difference between groups (baseline → 6 months) |
| Control symptoms dimension; Mean (SD) | 9.9 (3.8) (n=93) | -0.20 (3.0) (n=82) | 0.18 (3.3) (n=87) | 9.8 (3.9) (n=72) | 0.92 (3.5) (n=69) | 0.85 (3.9) (n=65) | 0.036 | 0.254 |
| Control illness dimension; Mean (SD) | 9.2 (2.0) (n=93) | -0.08 (1.6) (n=81) | -0.34 (2.0) (n=87) | 9.2 (2.0) (n=72) | 0.07 (1.6) (n=69) | -0.25 (2.1) (n=65) | 0.562 | 0.785 |
| Maintain function dimension; Mean (SD) | 13.8 (4.7) (n=93) | -0.01 (2.7) (n=81) | -0.08 (3.4) (n=87) | 13.3 (5.0) (n=72) | -0.26 (3.0) (n=69) | -0.08 (3.0) (n=65) | 0.590 | 0.995 |
| Global cardiac self-efficacy; Mean (SD) | 32.9 (8.4) (n=93) | -0.11 (5.4) (n=80) | -0.23 (6.8) (n=87) | 32.3 (9.1) (n=72) | 0.75 (5.5) (n=69) | 0.57 (6.5) (n=64) | 0.342 | 0.473 |

*Baseline value is 4 weeks post-discharge

DISCUSSION

The overall impression from the interview data in the qualitative study was that being affected by ACS meant being *aware that life is lived forwards and understood backwards* (Study I). The interviewees seemed to have a strong desire to link the past with the future to find an understandable elucidation to their illness and to optimise their health conditions in the future. The interpretation of the narratives suggests that the interviewees processed the perceived acute overwhelming phase at the same time as they tried to obtain a sense of inner security. Being affected by a health threat implies that the cognitive representations of one's illness are formed (Leventhal *et al.*, 1998).

Already during the hospital stay, patients formulated personal models, built on their understanding of how they recognised, interpreted and responded to a specific illness experience. According to the anthropologist Arthur Kleinman, this helps to cope with and understand both the disease and illness (Kleinman, 1980). Patients' models are personal and may differ from the ones given by the health care professionals, which are often generalised and based on the diagnosis rather than attuned to each patient's preferences. These models are connected to their own experience and perceptions of the disease and illness. Negative experiences can affect the development of these models and can make it difficult for patients to see their own resources as they may associate the ACS event with adverse outcomes. Conversely, patients with positive experiences may instead be more capable of seeing their own resources. With that in mind, the need of care attuned to each person's preferences is enhanced to capture different aspects of personal models.

A person-centred dialogue emphasises the value of listening to the patient's narrative, facilitating the identification of possibilities but also obstacles and finding ways to bridge over these in order to identify and gain access to the person's resources. According to the gPCC approach outlined in 2011 by Ekman and colleagues (Ekman *et al.*, 2011), the patient narrative is the point of departure followed by an agreement (partnership) and a documented gPCC plan jointly formulated by health care professionals and patients. The gPCC plan covers the patient's point of view but also accounts for the disease from a medical perspective to facilitate the achievement of patient goals during recovery and ultimately improve patient health outcomes. In this thesis, the gPCC approach (including the gPCC plan) served as a guiding principle to accomplish an RCT that evaluated the effects of a gPCC intervention in patients with ACS (Study III and IV).

Self-efficacy is embedded as a central concept in the gPCC approach because it addresses people's beliefs in their ability to perform the appropriate and targeted actions to achieve desired outcomes, rather than attempting to convince them of the value of certain activities (Bandura, 1997a). Therefore, it was considered the main patient reported outcome of the RCT. Disease-specific instruments are often used to evaluate the effects of an intervention because they usually are more

sensitive in detecting change than generic instruments (Wiebe *et al.*, 2003). Self-efficacy, as a general measure, has previously been validated in Swedish (Löve *et al.*, 2012). The CSES (Sullivan *et al.*, 1998) was psychometrically evaluated in a Swedish population with ACS, the S-CSES (Study II), to evaluate the effects of the RCT on a disease-specific instrument, addressing the challenges that arise as a result of the coronary disease.

The S-CSES was found to be a reliable and valid measure to evaluate specific CSE, and it was shown to consist of three underlying dimensions and one total summary score reflecting the global dimension of CSE (Study II). The first dimension refers to a person's belief in the ability to control the symptoms (chest pain, breathlessness), the second to a person's confidence in the ability to control the illness (contact health care, take daily medication) and the third to a person's confidence in the ability to maintain physical function. The possibility to assess three underlying dimensions and also be able to use a summary measure of CSE may be beneficial in further care of patients with ACS. The S-CSES and its dimensions can be used as a tool in clinical practice to integrate a patient's CSE into a person-centred dialogue. Low CSE is related to several health complaints, such as increased symptom burden, reduced physical function, worse overall health and quality of life as well as readmission to the hospital in patients with CHD (Sarkar *et al.*, 2007, Sarkar *et al.*, 2009). Given that patients possess various levels of CSE, the S-CSES may support a person-centred dialogue to help identify patients at risk for developing negative health outcomes as a consequence of the ACS event, which could contribute to adjust the recovery period to each patient's prerequisites in order to optimise future health.

Self-efficacy is related to PCC at a theoretical level since both concepts emphasise the person's own ability. Because the gPCC intervention builds on each person's preferences and resources, the GSES seems especially relevant and appropriate as an outcome measure as this scale mirrors a global confidence in the ability to perform a desired activity. The GSES is also well established (Luszczynska *et al.*, 2005) and was therefore set as the patient reported aspect of the primary endpoint. In the RCT, it was found that by using gPCC compared with usual care in patients with ACS, the recovery was improved (significantly improved GSE without increased need for readmission to hospital). The involvement of patients in a partnership, such as that in the gPCC approach during the recovery from a serious health event improved GSE, which may reflect on an earlier return to work or previous activity level (Study III).

Previous results using the gPCC approach have shown positive effects in patients with hip-fractures (Olsson *et al.*, 2006), hip-replacement (Olsson *et al.*, 2014) and chronic heart failure (Ekman *et al.*, 2012) where the length of hospital was noticeably reduced. Additionally, in patients with chronic heart failure, their uncertainty about the condition and medication decreased (Dudas *et al.*, 2013), the discharge process was improved (Ulin *et al.*, 2015) and showed favourable cost utilities (Hansson *et al.*, 2015). A randomised controlled study showed that PCC

is an important factor to improve quality of life in patients with chronic heart failure (Brännström and Boman, 2014). Internationally the term patient-centred is more used, that is, not fully focusing on the patient as person as in the gPCC approach, but still taking into account the patient's perspective. A systematic review that examined such a patient-centred approach showed a positive effect of patient-centred care on satisfaction and self-management (Rathert *et al.*, 2013). An RCT with a similar scope showed that a patient-centred modular prevention significantly improved the coronary risk profile and risk factor awareness among ACS survivors (Redfern *et al.*, 2009).

The RCT conducted in this thesis operationalised the partnership, including the patient narrative and the co-creation of the gPCC plan as core components of the gPCC approach (Ekman *et al.*, 2011) (Study III and IV). According to the presented results from the RCT, the gPCC approach is proposed as an underlying factor to improve GSE. The point of departure in the gPCC approach is the importance of knowing the patient also as a person with capacities and abilities to perform activities and achieve set goals which create the conditions necessary to establish an active partnership between the patient and health care professionals (Ekman *et al.*, 2011). Previous reports have shown that enhanced self-efficacy is a key component to facilitate self-management and is a predictor of future health status (Lorig and Holman, 2003). Greater improvement in self-efficacy at 6 months, as was the case in the outlined RCT in this thesis (Study III), has shown to be significantly associated with lower utilisation of care after 1 year, and thereby, reduced health care costs as well (Lorig *et al.*, 2001). Levels of self-efficacy are also associated with attendance in cardiac rehabilitation (Jackson *et al.*, 2005) and prediction of independent exercise over a 6-month period (Carlson *et al.*, 2001).

According to previous studies, it has been shown that a high self-efficacy is associated with several beneficial outcomes during cardiac disease recovery in terms of a healthier lifestyle (Sol *et al.*, 2011), self-management behaviours, psychological well-being, quality of life (Joekes *et al.*, 2007) and attendance to cardiac rehabilitation programs (Jackson *et al.*, 2005). Up to 2 years after a myocardial infarction, GSE was found to be positively associated with health-related quality of life (Brink *et al.*, 2012). Self-efficacy can be modified to influence and reinforce, and in patients with cardiac diseases, improved self-efficacy has been associated with concordance between health professionals' and patients' view on prescriptions of medications, diet and physical activity and also patients' ability to manage stress improved (Marks *et al.*, 2005). The gPCC intervention in Study III encompasses the systematic consideration of the patient's perspective and is based on the patient's narrative, the development of a team-based transparent partnership and documentation of the partnership in a co-created gPCC plan from in-hospital to primary care. In turn, this increases the patient's GSE (Study III).

A secondary endpoint in the RCT was to evaluate the effects of the gPCC intervention on specific CSE which addresses management of symptoms and maintaining physical functioning after a cardiac event, such as ACS (Study IV). The

results showed that the gPCC group increased their CSE more quickly in terms of controlling symptoms. After adjusting for disease severity and depression, to possess a high level of CSE is favourable since a low level is related to increased symptom burden, impaired physical function and lower health status and quality of life in patients with CHD (Sarkar *et al.*, 2007). The results in Study IV are in line with a recent pilot study in which patient-centred care was applied, by means of including individual aspects from the patients and not only the medical aspect. In that study, the intervention group reported higher CSE scores in the control symptoms dimension. Additionally, the intervention group had higher attendance to cardiac rehabilitation programs (Weibel *et al.*, 2014). However, in Study IV no differences between the groups were detected regarding the other dimensions in the S-CSES (i.e., control illness, maintain functioning and the global CSE dimension). After 6 months, the initial difference between the groups for control symptoms disappeared in time. This result may be explained by the time factor, that is, living with coronary disease for a long period of time leads to the development of strategies to cope with the disease (Buckley *et al.*, 2007). Altogether, the results from the present RCT (Study III and IV) raise questions regarding if general or disease-specific measures are most suitable to evaluate self-efficacy in PCC interventions based on the gPCC approach.

General and specific self-efficacy

Assessment of self-efficacy as a general or situation-specific construct is well discussed in the literature (Bandura, 1977b, Chen *et al.*, 2001, Luszczynska *et al.*, 2004). Self-efficacy stresses the belief in a person's capability to take on difficult or novel tasks and to cope with the difficulties arising from demanding situations in order to achieve desired outcomes (Bandura, 1977, Bandura, 1997b). According to Bandura, perceived self-efficacy should primarily be conceived in a situation-specific manner (Bandura, 1997b). Therefore, self-efficacy is generally understood as situation-specific, meaning that a person could have more or less steady beliefs in different domains or specific situations of functioning. Nevertheless, self-efficacy may also be conceived as a more general concept which instead refers to the global confidence in one's ability to deal with a range of demanding situations (Schwarzer R and Jerusalem M, 1995). GSE takes into account differences among people in their tendency to view themselves as capable of meeting task requirements in a wide range of contexts (Chen *et al.*, 2001). It has been suggested that GSE addresses a motivational trait while SSE represents a motivational state (Gardner and Pierce, 1998).

GSE may be preferable when the context is less specific, and when focusing on multiple behaviours simultaneously (Luszczynska *et al.*, 2004). General measures have demonstrated to be better suited for predicting general patterns of behaviour and may also be useful when people have to adjust their situation to multiple demands as a consequence of the illness (Bonetti *et al.*, 2001). Accordingly, people that possess high GSE are expected to succeed across a variety of task domains. To feel efficacious across tasks and situations, i.e. GSE, may expand into specific

situations, which is reflected by the positive correlation between GSE and SSE domains as physical activity, nutrition and smoking (Luszczynska *et al.*, 2005). A positive relation between GSE and specific CSE was also noticed in this thesis (Study II). Therefore, GSE may positively influence SSE across tasks and situations, that is, SSE is considered as a possible outcome of GSE. Being affected by ACS comprises a complex and demanding period where possessing a high GSE is a valuable resource to maintain motivation during recovery and act as a buffer in case of potentially demotivating failure. A successful recovery from ACS could serve as an example of mastery experience which increases a person's belief in their ability to cope with such an event, an experience that can be generalised to manage other challenges in life (Bandura, 1997b). SSE measured by the S-CSES is associated with the disease and since the patient sets the agenda in the gPCC approach, that is, setting individual goals based on their preferences instead of being guided to achieve goals that are predetermined and linked to the disease, generic instruments such as the GSE instrument may reflect the outcome of a gPCC approach better. Since PCC targets a wide variety of behaviours based on the patient's perspective, the GSE may be the most appropriate to evaluate a gPCC approach to reflect the effects.

Clinical implications

Self-efficacy in person-centred care practice

Self-efficacy is suggested to be a critical factor in the process of self-management and improved health outcomes. A person's belief in the capability to perform an action (self-efficacy), such as certain health behaviours, and expectations that the behaviour will lead to the desirable result are important facilitators of performance. The extent to which patients acquire and apply self-management does not primarily depend on their knowledge of the disease but rather on a range of personal factors, processes and resources unrelated to the disease (Bandura, 1977, Bandura, 1997b, Lorig and Holman, 2003). One way to attain successful self-management is to merge a patient's thoughts, feelings and behaviours with the treatment and patient goals during recovery.

Consequently, the concept of self-efficacy is especially useful in several health care contexts, not only during the recovery of an ACS event, because it comprises a guide for how self-efficacy beliefs can be improved. There are four main sources of self-efficacy that influence perception of GSE and SSE; mastery experience, vicarious experience, verbal persuasion and psychological and affective states (Bandura, 1997b). In this thesis, these four sources were addressed, separately or in combination, and integrated into a gPCC approach in order to increase self-efficacy (general and cardiac specific) in a population with ACS (Study III and IV).

Mastery experience

The most powerful source of self-efficacy is a person's successful execution of a behaviour or task. A successful accomplishment of the assignment increases a person's self-efficacy under the premise that the success must be attributed to the

person's own efforts and abilities. Instead, failures lead to decreased self-efficacy. Central in the gPCC intervention applied in this thesis was listening to the patients' narrative, which provided the basis for the creation of a gPCC plan (Study III and IV). The PCC dialogue helps identify and reinforce past successes and accomplishments, which can be used as facilitators. In the gPCC plan, patients set goals during the recovery period based on their abilities and interests. The goals were discussed and agreed upon with health care professionals and considered to be realistic and attainable according to each person's beliefs and conditions. For example, patients could set goals such as returning to work, be able to continue with everyday activities and hobbies or to increase their physical activity. During follow-up, the gPCC plan and its goals were discussed and evaluated to provide feedback on the performance and accomplishment of such goals can increase self-efficacy. The gPCC plan constituted the basis for the gPCC team visit. By evaluating and revising the gPCC plan according to each patient's progress regarding the attainment of their goals, the patients' self-efficacy is likely to increase. Setbacks to reach their goals led to revisions and adjustments of the gPCC plan, which was adapted to each person's situation. Thus, other realistic targets were set or that the initial goal were simplified into smaller, more feasible goals to achieve them stepwise and create conditions for increased self-efficacy under more reasonable prerequisites.

Vicarious experience

Self-efficacy can also be increased and modified by observing others in similar situations either succeed or fail. People can incorporate models consisting of other ways to cope with the situation or achieve set goals by observing people who have managed similar situations. No prior experience of the ACS event may be advantageous to increase self-efficacy through vicarious experience since that means that there is no basis on which to assess the capability. That is, the sensitivity of vicarious experience increases with the absence of personal experience. Patients in the gPCC intervention group raised several challenges that they wanted to overcome (Study III and IV). The narrative allowed the identification of resources, both personal and within their social network that could contribute and facilitate the attainment of the goal set in the gPCC plan. The person-centred dialogue allowed and facilitated patient communication so that successful role models could be identified within their social network (e.g., family, relatives and friends) to be examples of success and help increase patient self-efficacy.

Verbal persuasion

Verbal persuasion may originate from friends, colleagues or family members. Patients are likely to identify target goals in their narration from their network as role models, especially these that involve topics of personal efficacy. In the gPCC intervention, the establishment of a partnership between the patient and health care professionals was the core component initiated through the patient narrative which opened up the possibility to see the patient as a person with capabilities, goals, preferences and needs (Study III and IV). The partnership promoted a safe and supportive group environment through which the patients were able

to achieve success in life pursuits from their own perspective. The partnership is a valuable and powerful resource in the gPCC approach that can influence self-efficacy in clinical practice.

Physiological and affective states

The assessment of a person's capability may be influenced by the common physical symptoms such as chest pain and breathlessness (Study I, III and IV). Emotional arousal, including anxiety and fear, as a result of the ACS event may decrease perceptions of self-efficacy as these feelings are associated with vulnerability. Therefore, they reduce the ability to take on challenges posed by the disease. People may doubt their capability to perform behavioural changes and develop negative self-efficacy beliefs. Through a PCC dialogue such feelings can be explained as reasonable, given the situation, and with time the PCC dialogue can contribute to the development of coping strategies. The gPCC plan involves both obstacles and opportunities and emphasises virtue and strengths as personal resources that can serve as a counterweight to overcome adversity.

Methodological considerations

Qualitative and quantitative methods complement each other by representing outcomes as words and numbers. A qualitative research method is primarily aimed to describe and understand meanings of the phenomenon, for example, the experience of being affected by ACS, and not to generalise to a target population (Study I). The principle when collecting a population sample to describe a phenomenon (such as experiencing ACS) is that the participants must have experienced the actual event and have the ability to express it. In qualitative analysis, there are no fixed rules of sample sizes, and a smaller number of cases can generate a large amount of data for analysis (e.g., by interviews). The main point is to generate enough data to formulate meaning units and themes of the studied phenomenon (Polit and Beck, 2012). Trustworthiness in qualitative research refers to four criteria: credibility, dependability, confirmability and transferability, which are related to each other (Lincoln and Guba, 1985). To enhance the ability of getting rich narratives, the participants enrolled were both women and men in different age ranges, which gave a wide variation to their responses and quotations. Thus, the themes were exemplified and helped to clarify the findings. To further strengthen the credibility of the interviewees, follow-up questions were asked in order to verify statements. Dependability is closely connected to credibility (Polit and Beck, 2012); it was strengthened by the fact that the interviewees received the same instructions, started from the same opening question and were asked similar follow-up questions. All twelve interviews were conducted during the hospitalisation, suggesting that the patients were under similar conditions regarding their thoughts about the disease. Additionally, the memory of the onset of the disease was still present (Study I).

Nevertheless, there is always more than one way of understanding a text, and the interpretation of the study data represents one of several possibilities (Ricoeur,

1976). In the present study, the authors had a critical approach based on their previous understanding of cardiac care and secondary prevention in primary care. They critically reflected on competing interpretations of the narrative until agreement was achieved regarding the credibility of the presented findings. The latter can be seen as a criterion for conformability. To promote transferability, which is determined by the reader, the context, sample process, participants, data collection and analysis were thoroughly described. The presented findings are likely to be applied in context where ACS events are treated (Study I).

The quantitative studies in this thesis used well-established instruments (Study II–IV). Validity and reliability have been shown in the CSES (Sullivan *et al.*, 1998) and the Saltin Grimby Physical Activity Level Scale (Aires *et al.*, 2003). This is also the case for the GSES, which has been widely tested and used both nationally (Löve *et al.*, 2012) and internationally (Luszczynska *et al.*, 2005). In Study II, the CSES (previously not validated in Sweden) and its dimensionality were psychometrically evaluated by using confirmatory factor analysis. Confirmatory factor analysis was chosen for hypothesis testing of the existing model of the CSES in a Swedish population with ACS. The most important argument for a factor structure to be reliable and relevant is its replicability, which is confirmed by confirmatory factor analysis (Brown, 2006). Face validity is another form of validity that was used to assist the confirmatory factor analysis to assess whether the items in the CSES indeed measuring what they aim to measure and to confirm if some items may measure the same parameters. Convergence and discrimination were seen as subsets of construct validity and were tested using the Pearson's correlation coefficient. Further, Cronbach's alpha was calculated to decipher internal consistency (Dmitrienko *et al.*, 2007).

To evaluate the effects of the gPCC intervention, an RCT design was performed, considered as the gold standard as it protects against selection bias. Randomisation is necessary to balance unknown factors since only a part of the outcome can be explained by known factors (e.g., the variation of mortality in ACS can not only be explained by known factors such as age, comorbidity and cardiovascular risk factors). Randomisation is the only means of controlling for unknown and unmeasured factors as well as those that are known (e.g., age, gender) and measured (Odgaard-Jensen *et al.*, 2011). A part of the composite score in Study III was to evaluate the effects of the gPCC intervention regarding the return to work. Therefore, to obtain an equal sample regarding people who are either working or retired and minimise co-morbidity factors, an age limit of 75 years was selected. The same limit was also set in Study I and II in order to match the sample in Study III and IV.

The internal validity was considered by using predefined stratification steps and randomising a homogenous group to reduce bias caused by factors that could contribute to the measured effects (Study III and IV). To enhance the reliability and to prevent type 1 and type 2 errors, the level of significance was set at 0.05, and samples were sufficiently large. The external validity was satisfied accord-

ing to the number of participants randomised from both sites and followed up at three outpatient clinics and at all public primary centres in the greater metropolitan area of Gothenburg (n=43). In addition, a reliable follow-up period of over 6-month strengthened the generalisability of the study to other samples and settings (Polit and Beck, 2012).

The RCT in this thesis addresses a complex intervention and it comprises the interaction of several components, especially establishing the partnership through the patient's narrative, shared decision-making and the development of a gPCC plan (Study III and IV). The number and level of difficulty of the behaviours required by both health care professionals and patients contributed to the complexity of this trial (e.g., patients set different goals during recovery) and so did the number of organisational levels targeted by the intervention (2 hospitals, 3 outpatient clinics and 5 primary care centres). Moreover, the primary endpoint was a composite score involving several factors. In a complex trial, such as this, a single primary outcome may not make the best use of data and strict standardisation may be inappropriate. Thus, the intervention is more beneficial if it allows some adaptation to local settings. Lack of effect may reflect implementation failure rather than genuine ineffectiveness. A theoretical understanding is needed to explain how the intervention causes change (Craig *et al.*, 2008).

CONCLUSIONS

Self-efficacy is a valuable concept in the context of PCC on both a theoretical level and as an outcome measure. This thesis provides a blueprint that describes how self-efficacy beliefs can be enhanced by a gPCC approach for patients after an event of ACS. Early on during the hospitalisation, patients who were affected from an ACS event formed their own understandings of their illness, and were prepared to discuss their forthcoming goals with health care professionals to sustain their future health. Patients formulated personal models which required that health care professionals take into account each patient's perspective to develop personal health plans through a carefully conducted person-centred dialogue.

Evaluation of a gPCC approach in the RCT was found to be effective in laying the groundwork to improve self-efficacy. The establishment of a partnership, a joint agreement that mirrors both the perspective of patient and the health care professionals, is proposed as a mediating variable to facilitate the care chain and the single most important component in the PCC relationship. To evaluate the effects of PCC, generic measures are preferable to disease-specific instruments because gPCC originates in the person's preferences and resources and not in the disease. Enhanced strategies in terms of gPCC can advantageously be included in the care of persons after an event of ACS to improve their self-efficacy without worsening their clinical outcomes.

FUTURE PERSPECTIVES

PCC is advocated as an important component of a paradigm shift in health care that combines evidence-based care and medicine with the patient's understanding and knowledge of the illness and disease. This thesis build on the increasing number of studies and existing knowledge suggesting that a person-centred approach along the chain of health care is effective in improving both patient-reported and clinical outcomes. Self-efficacy beliefs were improved by a gPCC approach. Thus, this approach should be assessed in other settings and populations. Further trials are also necessary to elaborate on the relationship between generic and disease-specific instruments in relation to PCC. The benefit of enhanced self-efficacy in relation to patients' health outcomes and clinical implications should also be assessed further. Even though the findings of this thesis help fill the existing gaps in knowledge, many questions remain unanswered with regard to how patients and health care professionals experience and view a person-centred approach in health care.

This thesis can serve as a foundation for the development of person-centred models adapted to local settings and populations in future studies, which aim to evaluate the efficacy of PCC. Possibilities and obstacles of care should be researched to identify the current circumstances in which it is possible to apply a person-centred approach, the changes required and how these should be implemented. Implementing a person-centred approach with strict ethical standards requires a change of philosophy in health care, from one that is dominated by an objective and disease-oriented view where the patient is in the background, to a subjective view in which patients are seen as persons with abilities and resources that can assist their own care.

POPULÄRVETENSKAPLIG SAMMANFATTNING PÅ SVENSKA

Personcentrerad vård innebär att personen och inte diagnosen, är utgångspunkten för vård och omsorg. Människor med samma diagnos upplever och hanterar sin situation på olika sätt, en personlig hälsoplan utgår från evidensbaserad kunskap men varje persons unika förmågor och behov styr målen och hur de formuleras. Patienten blir en aktiv partner i sin egen vård och behandling. Ett begrepp som knyter an till personcentrerad vård är *self-efficacy* vilket inriktar sig på en persons tilltro till sin egen förmåga att kunna utföra ändamålsenliga handlingar för att nå ett önskat resultat, dvs. övertygelsen att kunna genomföra en uppgift för att nå ett uppsatt mål snarare än att bli övertygad och förvissad om att ett visst beteende kommer leda till ett angivet utfall.

Akut kranskärslssjukdom (AKS) är ett samlingsnamn för hjärtinfarkt och instabil kärlkramp. Denna avhandling omfattar fyra studier vilka undersöker hur det kan upplevas att drabbas av AKS samt utvärderar mätinstrument och effekter av personcentrerad vård bland patienter som insjuknat i AKS. I det första delarbetet har en kvalitativ metod använts och data har sedan analyserats med fenomenologisk hermeneutik. I övriga tre delarbeten har kvantitativ metod använts där data har analyserats med hjälp av deskriptiv statistik, konfirmatorisk faktoranalys, parametriska och icke parametriska test samt logistisk regression.

Det framkom att personer som drabbats av AKS skapar egna förklaringar till insjuknandet och är beredda att redan på sjukhus diskutera sina mål i syfte att optimera sin framtida hälsa. Som en följd av det behöver hälso- och sjukvårdspersonal aktivt och lyhört lyssna till patientberättelsen och i samråd med patienten forma en personlig hälsoplan. Hälsoplanen utgår alltid från patientens egen sjukdomsberättelse och blir ett viktigt redskap för att lyfta fram patientens resurser, behov och möjligheter. Planen involverar även det stöd som behövs för att nå de individuella målen under återhämtningsperioden, både från sociala nätverk och från hälso- och sjukvårdspersonalen.

Avhandlingen inkluderar en randomiserad kontrollerad studie. I gruppen som fick personcentrerad vård arbetade professionella och patient (närstående) tillsammans i team och beslutade gemensamt vad som skulle göras vilket gör patienten till en partner och ansvarig i planering och genomförande för att nå sina hälsomål. En uppföljning 6 månader efter sjukdomstillfället visade att en personcentrerad intervention som betonar partnerskapet mellan patienter och hälso- och sjukvårdspersonal genom vårdkedjan (sjukhus, öppenvård, primärvård) innebar en nästan tre gånger så stor chans att förbättras jämfört med en kontrollgrupp som fick sedvanlig vård. Förbättringen innebar att de som fick personcentrerad vård hade en större generell tilltro till sin egen förmåga, att de återgick till arbete eller till tidigare aktivitetsnivå och att de inte blev återinlagda på sjukhus för någon ny hjärthändelse.

I avhandlingen utvärderas också ett mätinstrument avseende tilltro till sin förmåga vid hjärtsjukdom vilket visade sig uppfylla krav för validitet och reliabilitet när det prövades i en svensk population med AKS. I den randomiserade kontrollerade studien framkom det att en personcentrerad intervention även påskyndar en persons självförtroende att hantera sina symptom relaterade till hjärtsjukdomen.

I personcentrerad vård har patienten möjligheten att ta kontroll över och hantera sin sjukdom och dess symptom, få en överblick av och relevant stöd i vård- och rehabiliteringsarbetet och därigenom känna sig trygg i vårdkedjan. Personcentrerad vård innebär en kulturförändring i vården, från ett som domineras av ett objektiviserande synsätt där sjukdomen står i centrum och patientens egen upplevelse av sjukdomen hamnar i skymundan, till ett subjektivt synsätt där patienten ses som en person med förmågor och resurser vilka används som en tillgång i vården. Personcentrerad vård innebär att patienten är en partner i vården vilket effektiviserar vårdkedjan från sjukhus till primärvård, ökar patientens tilltro till den egna förmågan att hantera sin sjukdom, vilket är associerat med en framtida förbättrad hälsa och minskad sjukvårdskonsumtion.

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APPENDIX 1

Swedish version of the cardiac self-efficacy scale

Nedan några frågor om självtillit

| | Ingen tilltro alls | Viss tilltro | Måttlig tilltro | Stark tilltro | Full- ständig tilltro |
|---|--------------------------|--------------------------|--------------------------|--------------------------|-----------------------------|
| | 0 | 1 | 2 | 3 | 4 |
| Hur stark är din tilltro att du kan: | | | | | |
| 1. Om du skulle känna bröstsmärta – kan kontrollera denna genom att ändra aktivitetsnivån | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Om du skulle känna andfåddhet – kan kontrollera denna genom att ändra aktivitetsnivån | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Om du skulle känna bröstsmärta – kan kontrollera denna genom att ta dina mediciner | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Om du skulle känna andfåddhet – kan kontrollera denna genom att ta dina mediciner | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hur stark är din tilltro att du vet: | | | | | |
| 5. När du ska kontakta eller besöka vårdgivare angående din sjukdom | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Hur du får ansvarig vårdpersonal att förstå dina hjärtproblem | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Hur du ska ta dina hjärtmediciner | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Hur mycket utövning av fysisk aktivitet som är bra för dig | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hur stark är din tilltro att du kan: | | | | | |
| 9. Bibehålla dina vanliga sociala aktiviteter | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Bibehålla dina vanliga aktiviteter i hemmet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Bibehålla dina vanliga aktiviteter utanför hemmet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Vara sexuellt aktiv | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Utöva fysisk träning (svettas och ökad hjärtfrekvens) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Cardiac self-efficacy scale: Swedish translation with permission from Professor Mark D Sullivan.
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APPENDIX 2

Swedish version of the general self-efficacy scale

1. Jag lyckas alltid lösa svåra problem om jag bara anstränger mig tillräckligt.
2. Även om någon motarbetar mig hittar jag ändå utvägar att nå mina mål.
3. Jag har inga svårigheter att hålla fast vid mina målsättningar och förverkliga mina mål.
4. I oväntade situationer vet jag alltid hur jag skall agera.
5. Till och med överraskande situationer tror jag mig klara av bra.
6. Tack vare min egen förmåga känner jag mig lugn även när jag ställs inför svårigheter.
7. Vad som än händer klarar jag mig alltid.
8. Vilket problem jag än ställs inför kan jag hitta en lösning.
9. Om jag ställs inför nya utmaningar vet jag hur jag skall ta mig an dem.
10. När problem uppstår kan jag vanligtvis hantera dem av egen kraft.

Response format

- 1 = Tar helt avstånd
- 2 = Tar delvis avstånd
- 3 = Instämmer delvis
- 4 = Instämmer helt

Swedish version of the general self-efficacy scale; Marcus Koskinen-Hagman, Ralf Schwarzer & Matthias Jerusalem, 1999. <http://userpage.fu-berlin.de/~health/selfscal.htm>