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**Peer Mentoring**  
**A Complementary Support to Persons after an**  
**Acute Myocardial Infarction**

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**Peer mentoring - A complementary support to persons after an acute myocardial infarction**

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*Till det varma minnet av mamma och pappa  
Ni finns med mig, och för alltid, i mitt hjärta*

## **Peer mentoring - A complementary support to persons after an acute myocardial infarction**

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### **ABSTRACT**

The overall aim of the thesis was to investigate the experience of having an acute myocardial infarction (AMI) in newly afflicted persons living in sparsely populated counties, and whether an intervention with peer mentors would provide support by affecting the perception of illness, health related quality of life and everyday life. The aim was also to describe the support of peer mentors from their perspective and what the mentoring meant to them. The thesis was based on four empirical studies (**I-IV**) and had a prospective, longitudinal, quasi-experimental, comparative design. A suitable sample was recruited, comprising 72 individuals who were newly afflicted with an AMI for the first time; 34 of them were offered contact with a peer mentor, while 38 were not. Furthermore, 34 peer mentors participated in the project. The results were based on data collected from 28 individuals with mentors, 33 individuals without and 22 peer mentors. In studies **I** and **III**, qualitative approaches were used based on individual interviews with 20 newly afflicted individuals with (n=11) and without (n=9) mentors one year after AMI. The aims were to describe individuals' perceptions of the psychosocial consequences of an AMI and of their access to support one year after the event (**I**) and to describe individual perceptions of their lifestyle and support, 1 year after an AMI with or without mentorship (**III**). Study **II** was quantitative, consisting of data from questionnaires IPQ-R and SF-36 answered by 61 newly afflicted individuals with (n=28) and without (n=33) mentors. It aimed to investigate whether changes in illness perception and health-related quality of life occur over time after an intervention with peer mentors 1, 6 and 12 months after an AMI. Study **IV** had a mixed design and included peer mentors with the purpose to describing the personal meaning of being a peer mentor, for a person recovering from an AMI. Data consisted of individual interviews (n=15) and some data from IPQ-R and SF-36 that were provided on two occasions (n=22). All of the interviews (**I**, **III**, **IV**) were digitally recorded and analysed by qualitative content analysis, while the quantitative studies included descriptive data and were further compared using analysis of variance (ANOVA) (**II**) and the paired-sample *t*-test (**IV**).

The results from all four studies are interpreted and presented together, and they show differences and similarities between the newly afflicted with or without peer mentors, and the peer mentors. The results comprise six main areas; *the meaning of becoming a person with an AMI* (I, II, III) pointed toward an awareness of the situation expressed both in positive and negative terms, as being thankful or of being afraid of having a second AMI. *View at health care* (I) indicated that follow-up after discharge was sometimes a positive experience but more often resulted in dissatisfaction with this part of the health-care system. *Consequences* (II) showed significant effects between groups in the dimensions 'consequences' and 'timeline acute/chronic' (IPQ-R), with higher mean values (=negative) for those without mentors and a significant effect of time in both dimensions. There were also physical consequences for many of the participants (I, II, III, IV) as well as psychological consequences (I, II, IV). *Everyday life* (I, III) was affected by AMI that sometimes limited activities. There were demands to change areas of life-style that were perceived as both positive and negative. *Health* (II, III, IV) showed that health increased for most individuals during the year, as confirmed by significant values for time for those newly afflicted. The peer mentors showed a decrease in mean values but expressed that they felt healthier after compared with before their commitment. *Meaning of support* (I, IV) indicated that families and relatives had an important, supportive role for newly afflicted participants. The mentorship showed that the relationship was, in some cases and for different reasons, unsuccessful. However, most of them were satisfied, and new friendships arose. More of the mentors felt pride and were thankful because their experience was shown to be valuable to others in addition to themselves.

The results were synthesised using the Human Becoming nursing theory, which confirmed that recovery after an AMI is a process that occurs over time in which that those afflicted must accept and be comfortable being a person who is afflicted by an AMI. Some tendencies indicated an advantage for the newly afflicted participants who had received contact with a peer mentor. Conclusion: Because the mentor had experienced the same event, the relationship contributed to the security of the mentee. The peer mentors matured with the task because they felt that their experience was valuable and they felt unique.

Keywords: Illness perception, Intervention, Longitudinal, Quality of life, Quasi-experimental, Recovery, Rural, Social support

## **Kamratstöd - Ett kompletterande stöd till personer efter en akut hjärtinfarkt.**

Lena Junehag (2014)

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I det svenska sammandraget används begreppet *mentor* (=kamratstöd) som en översättning av *peer mentor*. I avhandlingen används begreppet *newly afflicted* genomgående, här översatt till *nyinsjuknade*, även ett år efter hjärtinfarkten.

## **SAMMANDRAG**

Övergripande syfte i avhandlingen var att studera erfarenheter av att drabbas av en akut hjärtinfarkt (AHI) för nyinsjuknade personer, boende i glesbygdslän, och om en intervention med kamratstöd i form av mentorer skulle kunna innebära ett stöd, genom att påverka deras sjukdomsuppfattning, hälsorelaterade livskvalitet och deras vardagsliv. Syftet var även att beskriva mentorernas stöd utifrån deras perspektiv, och vad mentorskapet har betytt för dem.

Avhandlingen är baserad på fyra studier (**I-IV**) och har en prospektiv, longitudinell och kvasiexperimentell, jämförande design. Ett lämpligt urval utgjordes av 72 personer som nyligen hade drabbats av AHI första gången. Av dessa erbjöds 34 att få kontakt med en mentor medan 38 inte erbjöds detta. Dessutom deltog 34 mentorer. Det slutgiltiga resultatet i avhandlingen baserades på data som samlats från 28 personer med mentor, 33 utan mentor samt av 22 mentorer. Studie **I** och **III** utgick från kvalitativ metod, baserat på individuella intervjuer med 20 av de nyinsjuknade med mentor (n11), och utan mentor (n9) ett år efter deras AHI. Syftet var att beskriva individuella erfarenheter av psykosociala konsekvenser i samband med en AHI, och deras tillgång till stöd ett år efter händelsen (**I**), samt att beskriva individuella uppfattningar om deras livsstil och stöd ett år efter AHI, med eller utan mentorskap (**III**). Studie **II** var kvantitativ och utgjordes av data från enkäter; IPQ-R och SF-36, som besvarades av 61 nyinsjuknade med mentor (n28) och utan mentor (n33), i syfte att undersöka om förändringar i sjukdomsuppfattning och hälsorelaterad livskvalitet förekommer över tid, efter en intervention med mentorer 1, 6 och 12 månader efter AHI. Studie **IV** hade en mixad design och inkluderade mentorer med syfte att beskriva den personliga betydelsen av att vara mentor, under loppet av ett år, för en person under återhämtningen efter AHI. Data bestod av individuella intervjuer (n15) samt en del data från IPQ-R och SF-36, besvarat vid två tillfällen. Samtliga intervjuer (**I**,

III, IV) spelades in digitalt och analyserades med kvalitativ innehållsanalys, medan de kvantitativa studierna innefattade beskrivande data, samt dessutom analyserades med variansanalys (ANOVA) (II) samt parvisa *t*-test (IV).

Resultat från samtliga fyra studier är tolkade och presenterade gemensamt, och visar på skillnader och likheter mellan de nyinsjuknade med eller utan mentor, samt mentorerna. Resultaten utgörs av sex huvudområden: *Innebörd av att bli en person med en AHI* (I, II, III) tyder på en medvetenhet om sin situation, och som uttrycks i både positiva och negativa ordalag, som att vara tacksam eller att vara rädd för att få en ny AHI. *Syn på sjukvården* (I) antyder att uppföljningen efter utskrivning i vissa fall var en positiv upplevelse, men flera var missnöjda med den delen av vården. *Konsekvenser* (II) visade signifikant effekt mellan grupperna för dimensionerna 'konsekvenser' och 'tidslinje akut/kronisk' (IPQ-R) med högre medelvärden (=negativt) för dem utan mentor. Dessutom var det signifikant effekt för tid i båda dimensionerna. Det förekom även fysiska konsekvenser för flera av deltagarna (I, II, III, IV) liksom psykologiska konsekvenser (I, II, IV). *Vardagslivet* (I, III) påverkades av AHI genom att den i vissa fall hindrade dem från fysiska aktiviteter. Det fanns krav på dem att förändra delar i deras livsstil, vilket kunde uppfattas som både positivt och negativt. *Hälsa* (II, III, IV) visade att de flestas hälsa hade förbättrats under året, vilket bekräftades med signifikanta värden för tid hos de nyinsjuknade. Mentorerna hade däremot sjunkande medelvärden men uttryckte att de mätte bättre efter sitt uppdrag, än innan. *Betydelsen av stöd* (I, IV) visade att familjer och närstående hade en betydelsefull roll för de nyinsjuknade. Mentorskapet för dem med mentor samt mentorerna visade att relationen i vissa inte hade fungerat, av olika anledningar. Trots allt var ändå de flesta tillfreds, och nya vänskapsförhållanden hade uppstått. Flera mentorer kände sig stolta och var tacksamma för att deras erfarenheter hade visat sig värdefulla för andra, men även för dem själva.

Resultaten syntetiserades med omvårdnadsteorin *Human Becoming*, som bekräftade att återhämtningen efter en AHI är en process som förekommer över tid, och innebär att acceptera och känna sig bekväm med att vara en person som drabbats av AHI. Det fanns vissa tendenser till att det var en fördel för de nyinsjuknade att ha kontakt med en mentor. Slutsatsen var att eftersom mentorerna hade genomgått samma händelse, bidrog det till trygghet. Mentorerna hade växt med uppgiften, eftersom de kände att deras erfarenheter var värdefulla, och att de var unika.

Nyckelord: Glesbygd, Intervention, Kvasi-experimentell, Livskvalitet, Longitudinell, Sjukdomsuppfattning, Social support, Återhämtning

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## LIST OF PAPERS

This thesis is mainly based on the following four papers, herein referred to by their Roman numerals:

**I** Junehag, L., Asplund, & Svedlund, M. (2014). A qualitative study: Perceptions of the psychosocial consequences and access to support after an acute myocardial infarction. *Intensive and Critical Care Nursing*: **30**, 22-30.  
doi.org/10.1016/j.iccn.2013.07.002

**II** Junehag, L., Svedlund, M., & Hochwälder, J. Illness perception and health related quality of life after an acute myocardial infarction – an intervention with peer mentors. Submitted

**III** Junehag L., Asplund K, & Svedlund, M. (2014). Perceptions of illness, lifestyle and support after an acute myocardial infarction. *Scandinavian Journal of Caring Science*: **28**, 289-296. doi: 10.1111/scs.12058

**IV** Junehag, L., Hochwälder, J., & Svedlund, M. Meaning of being a peer mentor for a person recovering from an acute myocardial infarction. Submitted

## **Abbreviations**

AMI	- Acute Myocardial Infarction
CCN	- Coronary Care Nurse
CCU	- Coronary Care Unit
HRQoL	- Health Related Quality of Life
IPQ-R	- Revised Illness Perception Questionnaire
SF-36	- Short Form 36 questionnaire
PCS	- Physical Health
MCS	- Psychological / Mental Health

## **Pre-face**

This thesis focuses on the ability of people to share valuable experiences with one another. A nursing perspective aims to clarify illness from individual perceptions rather than from the perspective of disease. The core nursing values are to respect the vulnerability of and to struggle to adhere to the perspectives of individuals (Swedish Society of Nursing, 2010). For me as a nurse and human being, is it important to strengthen people who suffer from an illness, as well as their families' capacity to cope with difficult situations. One of the most essential tasks in nursing care is to prepare patients for their discharge from the hospital. My clinical approach is to adhere the 'hands off' technique because I believe in people's own capacity to manage difficulties with support. I have no specific professional experience in coronary care. However, as a private person, I know what those afflicted with heart conditions experience. Therefore, when I was offered the ability to complete this partially planned project, I accepted it with delight.

Dialogues with the participants provided the insight that crises in relation to serious events are universal and independent of cause, life situation or age. I have a long experience working in paediatric care, as a neonatal nurse. There are similarities between parents' reactions when their child is born unexpectedly premature or sick and between those affected by stroke and those close to them, and of course between men or women afflicted with an acute myocardial infarction (AMI) and their families. It is common for these individuals to be unsure whether they can trust the future or what the consequences of this life event will be. In other words, there are similarities in the needs and reactions of all people in a crisis situation, regardless of the nature of the problem, i.e., they have been placed in a situation that has shaken their life in a fundamental way and that affects their everyday life.



## INTRODUCTION

AMI is a common medical condition and a frequent cause of suffering and death worldwide (Thygesen, Alpert, & Harvey, 2007). The decreased death rate due to AMI during the last three decades implies an increased number of survivors returning to their everyday life. Many patients stay at the coronary care unit (CCU) for only 3-4 days after they have had an AMI (Baigi, Hildingh, Virdhall & Fridlund, 2008). A shortened hospital stay and sick leave post-AMI suggests that there are new demands for afflicted individuals and on the time provided for recovery. Care and rehabilitation tend to have medical overtones aimed at healing physical symptoms. However, many people associate AMI with death (Ostergard Jensen & Petersen, 2003). This parable means that people with a life-threatening event such as an AMI often experience an existential crisis, which results in, for example, emotional distress and anxiety (Alsén, Brink, Persson, Brändström, & Karlson, 2010; Eriksson, 2009). Therefore, it could be valuable to obtain support from someone who has experienced the same illness or event (Arndt, Murchie, Schembri & Davidson, 2009; Hanssen, Nordrehaug & Rokne Hanestad, 2009).

## BACKGROUND

To examine the subject field, the literature was searched in databases with different subject fields, for example, nursing, sociology and psychology. Literature was also found by references and/or by key words in articles, or by recommendations from colleagues.

### Perspectives on disease, illness and health

The view of disease has been dominated by the biological model for a long time, i.e., a focus on the physical condition without consideration of the behaviours or social and psychological parts of the individual (Engel, 2004). A diagnosis describes a disease, i.e., related to medical science through symptoms "*but a diagnosing disease has more subtle implications as well*" (Chiong, 2004). Consequences for patients have been that they were seen as a 'disease' rather than as a person afflicted by a disease (Morse & Johnson, 1991). However, the contexts of 'symptoms and disease' have evolved since the 19<sup>th</sup> century; from a diagnosis based on clinical criteria to symptom-based diseases (Aronowitz, 2004).

Illness is the negative experience caused by a disease and is expressed in terms of suffering or dysfunction. However, the feeling of illness can occur without a diagnosis (Tengland, 2005), i.e., illness is a changeable process that usually occurs in relation to feeling sick or when there are symptoms (Leventhal, H, Diefenbach, & Leventhal, E., 1992). The illness perspective is the patient's perspective and the

social context. Consequently, the application of a model of illness includes the mind and body. Furthermore, a holistic view also includes the social situation and environment of the individual and takes into account that the person has a history and a future (Morse & Johnson, 1991).

Reactions in connection to illness differ between people, for example how they view their situation after an AMI. A common reaction is to ask, 'why me'? (Alsén et al., 2008; Brink, Karlsson & Hallberg, 2006; Ostergaard Jensen & Petersson, 2003). An unexpected event may imply a crisis, which may initiate a chain of reactions that have a greater psychological effect when a physical disease exists (Cullberg, 1975). This means that when someone is affected by illness, that individual's physical, psychological and social life will also be influenced. How it is experienced by the individual (Morse & Johnson, 1991) depends on his or her cultural background and approach to health and illness (Ostergaard Jensen & Petersson, 2003). One perception of AMI is that it is an acute condition, while medically, it is regarded as a chronic condition (Brink et al., 2006; Wiles & Kinmonth, 2001). However, despite being a chronic condition, it does not signify a sedentary life (Brink et al., 2006; Steen Isaksen & Gjengedal, 2006).

Human health is considered natural, while an unhealthy state occurs because of limitations in the ensemble within and outside of a person. Subjective health is not a static condition and proceeds from the individuals' own experience (Eriksson, 2000). Health is defined philosophically with a holistic view of human beings and is one of the fundamental tenets of nursing (Swedish society of nursing, 2010). The World Health Organisation (WHO) conforms to the Charter of the United Nations presenting the basic principles of health. This definition is as follows, according to the two first sentences:

*"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (WHO, 2005).*

## **Quality of life**

Quality of life (QoL) does not describe a certain phenomenon, i.e., the concept is abstract and not easy to define simply, but is seen as an umbrella that includes different criteria. In a study, the meaning of QoL is described as two essential domains and indicators that usually are measured. Domains include well-being from the perspective of the individual, for example, social relationships, physical well-being and environment. Indicators are described as quality outcomes, for

example, consequences after an intervention (Verdugo, Schalock, Keith, & Stancliffe, 2005). The WHO explains QoL as comprising six domains in an instrument guide (measure of QoL): Physical; Psychological; Level of Independence; Social Relationships; Environment; Spiritual/Religion/Personal Beliefs. Furthermore, clarifications of each domain are provided, for example, energy and fatigue, activities, social support, home environment, health and social care, accessibility and quality (WHO, 2012). Following is a short definition of QoL:

*“Individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 2012).*

It is not easy, and it may not even be possible, to separate the concept *Health Related Quality of Life (HRQoL)* from QoL. In a systematic review of HRQoL models, including 100 articles published over 10 years (1999-2010), the authors searched the content because of alternating use. The authors established huge variations in the models and in the concepts that were used. They recommended future investigations and interventions comparing outcomes, and not the creation of new models but the development of existing ones (Bakas et al., 2012).

## **Acute myocardial infarction**

Many people are afraid of having an AMI, and one of the most common symptoms that cause people to seek emergency care is unexplainable chest pain (Jerlock, Gaston-Johansson, Kjellgren & Welin, 2006). AMI counts for cardiovascular disease (CVD), and the definition includes, among several criteria, necrosis in a portion of the heart (Socialstyrelsen, 2008, 2010; Thygesen et al., 2007). CVD is highly preventable, and according to the WHO, it is a high priority to prevent and control the globally increased number of patients with CVD (WHO, 2011).

Since 1998 in Sweden, the Swedish National Board of Health and Welfare has been collecting and publishing a register with statistics on every person living in Sweden and diagnosed with and receiving care for AMI. During 2001, the number of patients diagnosed and treated in the hospital increased as a direct result of new diagnosis criteria that were introduced that year. However, from 2001 to 2011, the incidence of AMI decreased by 25% both men and women. Despite this decrease, approximately 40 000 people per year in Sweden suffer an AMI, 60% of whom are men and 40% women; however, the risk of death as a consequence of an AMI has never been lower. The number of people in Sweden who died from an AMI has decreased radically since 1995 (Socialstyrelsen, 2013a) from 41% to 26% (2012) of men and from 45% to 30% (2012) of women who died within 28 days of suffering

an AMI. The gender difference is that the women are older than the men (Socialstyrelsen, 2013b).

Certain factors involve a greater risk of being afflicted by an AMI. For example, working situations with high stress and high demands have been noted to be a risk factor, particularly in individuals with no control over the situation (Socialstyrelsen, 2009; 2013a). However, an opposite result was observed in a meta-analysis that included 13 cohort studies in Europe comprising 197 473 person. The results of that study showed a low association ( $\approx 3.4\%$ ) between job strain and cardiovascular disease (Kivimäki et al., 2012). However, the older population suggests that AMI as a cause of death is increasing worldwide because a longer life results in a higher risk of having an AMI (Hedner, 2010; Wiles & Kinmonth, 2001; Yusuf, Reddy, Ôunpuu, & Anand, 2001). Other important risk factors are education level and, in particular, sex and heredity (Socialstyrelsen, 2013a; 2013b). Heredity is a risk factor especially for death due to AMI before the age of 60 (van Dis, Kromhout, Boer, Geleijnsne, & Verschuren, 2011). In some cases, heredity includes inherited lifestyle habits that are unhealthy. An unhealthy lifestyle and psychosocial risk factors contribute to most AMIs. Unhealthy lifestyle habits include smoking, unhealthy eating habits, physical inactivity, too much alcohol, overweight status, high blood pressure and high lipoprotein levels (Hedner, 2010; Socialstyrelsen, 2008; WHO, 2011; Yusuf et al., 2004).

Anxiety in relation to AMI is rarely studied despite the threat to those afflicted (Moser, 2007), and psychosocial risk factors have been paid little attention compared to other contributors. However, a study accomplished six weeks after discharge did show that low access to social support was a psychosocial risk factor (Orth-Gomér, Rosengren & Wilhelmsen, 1993). A study including 912 patients aimed to investigate the level of anxiety and showed an increased risk for complications, such as a re-infarction, during hospitalisation in patients with a high degree of anxiety. The authors noted deficiencies in procedures and support to manage anxiety (Moser, 2007).

## **Recovery after an acute myocardial infarction**

In Sweden, guidelines are formulated by the National Swedish Board of Health and Welfare, and they indicate how care and rehabilitation associated with AMI should be conducted. These guidelines have been issued by the Swedish government to avoid commercial interests. The main aim of secondary prevention is to prevent a relapse and/or complications after an AMI: 'to optimise cardiac patients' physical, psychological and social function'. According to the guidelines, lifestyle factors and changes should be made, such as lifestyle habits, treatment of



obesity, encouraging physical activity, stopping smoking, and medical treatment of hypertension and high levels of lipoproteins (Socialstyrelsen, 2008; 2009).

### **Impact on everyday life**

After AMI, afflicted persons experience indescribable fatigue and weakness. This weakness and decreased energy has been described as the worst effect of AMI, irrespective of other medical problems (Alsén, Brink, Brändström, Karlson, & Persson, 2010a; Brink et al., 2006; Kristofferzon, Löfmark, & Carlsson, 2007). Furthermore, anxiety and fear negatively influences quality of life and health, increasing the risk of having a second AMI (Mierzyńska, Kowalska, Stepnowska, & Piotrowicz, 2010). More sufferers feel uncertain of their body and often find it difficult to feel serenity compared with before the event. After an AMI, there is a process of learning to live with and manage this insecurity (Tod, 2008). Such changes are not necessarily negative. In some cases, they provide an opportunity for reorientation and a second chance at life with new and better perspectives on life and the world (Brink et al., 2006; Svedlund & Danielson, 2004; Tod, 2008).

Women afflicted by an AMI struggle to recover and regain a normal life, albeit with limitations (Svedlund & Danielson, 2004). Others have less control and ponder death and the risk of re-infarction. This group may lack confidence in their ability to influence their recovery and health, and consequently, they lack motivation and experience feelings of sadness and anxiety (Alsén et al., 2008; Tod, 2008). Female AMI sufferers and their partners were interviewed, and the women did not recognise themselves as the person they were before the AMI, and similarly, they largely kept their feelings to themselves for the sake of their partner (Svedlund & Axelsson, 2000). A systematic review including 20 articles sought to investigate how partner relationships are affected when one person has an AMI and confirmed that relationships can change after an AMI. Five themes were characteristic of this change; overprotection, communication deficiency, sexual concerns, changes in domestic roles and adjustment to illness (Dalteg, Benzein, Fridlund, & Malm, 2011).

### **Managing everyday life**

Despite a short hospitalisation after an AMI (Baigi et al., 2008), little attention is directed at the information needed by AMI sufferers after discharge from the hospital. Most of the information is general, focusing on technical data and medicine, and it is difficult to determine the information that is relevant and useful for the individual (Hanssen, Nordrehaug, & Rokne Hanestad, 2005; Ostergaard Jensen & Petersson, 2003). Focus group interviews performed 3 and 5 months after discharge were performed in people with an AMI. These people considered the information they had been provided about recovery to be incorrect with respect to

both the physical and the psychological conditions that could arise. They felt safe when receiving care at the CCU because they were sufficiently informed about AMI and its treatment during the acute phase. However, new symptoms emerged during recovery, and they had no one to turn to with questions (Hanssen et al., 2005). People who have had an AMI often express uncertainty about their life situation and about the advice they have been given about treatment, existential threats and how to prevent another AMI (Ostergaard Jensen & Petersson, 2003). A shorter hospitalisation places greater demands on care planning at discharge. However, people with an AMI and their relatives living > 50 km from hospitals in Australia (=rural area in Australia) were followed in a study before, during and after discharge from the hospital. The results showed that there were shortages in care planning and that the information provided was too brief. The afflicted individuals experienced feelings of a lack of safety, and furthermore, the 'carers' responsibility was too large after discharge (Williams et al., 2006).

Some who do not ponder existential questions think about underlying causes as universal. Those people seem to be more satisfied and manage to live a normal life because life after discharge depends above all on personality, attitudes and access to social networks. People with self-confidence seem to believe in their own capacity to prevent a re-infarction, while those who place their trust in nursing staff and relatives show less motivation to control their illness (Alsén et al., 2008). People who are aware of their illness and use adequate coping strategies may recover with increased control and fewer negative consequences, which decreases feelings of stress (Brink et al., 2006; Svedlund & Axelsson, 2000; Wyer, Earll, Joseph, & Harrison, 2001). The ability and willingness to believe in the future and a sense of humour, in addition to a good physical condition, make it easier to manage the changes after an AMI (Ostergaard Jensen & Petersson, 2003).

Many people believe that a 'small' AMI indicates a chance of complete recovery. Some persons who recovered less well than they had expected at 4 months after an AMI, felt vulnerable and had changed their perception about the seriousness of AMI (Wiles & Kinmonth, 2001). To understand and reevaluate coping ability, it is necessary to know *what* the person has to manage. Coping is a continuous process of changeable valuations that depend on the person as well as the environment, both physical and spiritual. The concept has been described as a realistic condition with a desire to understand the situation (Jerlock et al., 2006; Lazarus & Folkman, 1984).

### ***Lifestyle changes***

Physical activity for 30 minutes per day is recommended for all persons; however, this is not sufficient for AMI patients (Jerlock et al., 2006; Socialstyrelsen, 2008). The occurrence of AMI, as an acute condition, impacts the willingness of people to

implement lifestyle changes because they assume that a serious AMI leads to death or serious disease (Brink et al., 2006; Condon & McCarthy, 2006). Most afflicted persons have a high motivation to return to earlier activities even if their health condition compels them to introduce changes. Successful rehabilitation requires a new orientation and an active approach, but sometimes health problems caused by the AMI influence the physical capacity (Brink et al., 2006). However, for many AMI sufferers, changes in lifestyle tend to be retained for a limited period and possibly linked to denial of their own condition (Svedlund & Axelsson, 2000; Wiles & Kinmonth, 2001). One problem with individuals who have recovered well appears to be lack of motivation to maintain long-term lifestyle changes (Wiles & Kinmonth, 2001), which must be investigated from a social perspective (Condon & McCarthy, 2006). When people who had experienced an AMI were divided into two groups that received different length of exercise during their recovery, there were no differences between the groups about their willingness to exercise 18 months after their AMI (Hansen et al., 2010).

### **Formal support**

Interpretations from the National Board of Health and Welfare indicate that an individual with an impaired capacity should be offered support based on the individual's needs to provide him or her the chance to be an active part of society (SOSFS 2008:20, §2). The results from a study of 200 women afflicted with AMI showed that their need for information was greatest during the first 3 months post-AMI (Hildingh & Fridlund, 1997). Rehabilitation programmes after AMI are usually initiated approximately 6-8 weeks after discharge (Hanssen et al., 2005; Murphy et al., 2011). Those with an AMI need organised training in the form of physical exercise and should be offered this regularly by physiotherapists for 3-6 months after the AMI (Socialstyrelsen, 2008). Cardiac rehabilitation could include the determination of whether someone is affected with, for example, anxiety, and to offer help to this person (Worcester & Le Grande, 2008). However, some patients choose not to participate in rehabilitation programmes after an AMI; motivational factors remain to be researched (Alsén et al., 2008; Wyer et al., 2001), but some persons choose not to participate due to long commuting distances to the hospital (Wyer et al., 2001). However, the converse can also be true; for example, patients outside a metropolitan area were excluded from a study because (according to the researchers), they could not participate in an eight-week secondary prevention program due to the long commuting distances (Murphy et al., 2011).

Psychological care and support should be a natural consequence of an AMI (Mierzyńska et al., 2010). Support groups have proven to be a successful way to obtain support in different contexts. One systematic review of studies including self-help groups after an AMI aimed to establish evidence that such groups could act as resources during the time of rehabilitation (Jackson, Gregory & McKinstry,

2009). Meeting with others with similar experiences of a serious disease can be a relief and may be the most important factor in groups participating in health-promoting programmes (Hanssen et al., 2005; Steen Isaksen & Gjengedal, 2006). Focus group interviews conducted with persons afflicted with an AMI who participated in cardiac rehabilitation programmes in the hospital indicated a stronger fellowship and friendship between them compared with other sufferers, who trained alone at home with support from a hospital (Jones, Greenfield & Jolly, 2009). Another study with focus groups confirmed this importance. Their meetings were full of ironic humour, expressed in questions such as 'So you're still alive?' They had suffered from the same disease and shared their experiences with one another (Steen Isaksen & Gjengedal, 2006).

### **Informal support**

A study of general strategies for coping with negative life events showed that women made greater use of emotional coping strategies compared with men (Jerlock et al., 2006). The important support role of family and relatives was confirmed by people afflicted with an AMI, particularly at the beginning of their recovery after discharge (Eriksson et al. 2009). Emotional support has been ranked highest by people afflicted with an AMI (Hildingh & Fridlund, 1997; Ostergaard Jensen & Petersson, 2003), and both personal and professional emotional support can help to manage the condition (Almerud et al., 2008; Wingham, Dalal, Sweeney, & Evans, 2006). AMI sufferers who were asked to rate their access to emotional support showed a lower level at the rating compared with a healthy control group (Almerud et al., 2008). However, for some, the 'new life' may imply feelings of guilt because there is a greater need for help and support from those nearest to them (Ostergaard Jensen & Petersson, 2003; Svedlund & Axelsson, 2000). Most of them who are afflicted with an AMI appear confident in their own capacity to manage and take own responsibility. They want support, but many find that their families see them as sick and are overprotective (Alsén et al., 2008; Hanssen et al., 2005; Ostergaard Jensen & Petersson, 2003; Svedlund & Axelsson, 2000; Svedlund & Danielson, 2004).

Some gender differences may occur because men have mentioned that support from friends and nurses is important (Kristofferzon et al., 2007). Another valuable source of support is other patients; they listen and provide the individual with a feeling of being part of a team (Hansen et al., 2005). Investigations conducted at both 3 and 12 months post-AMI showed that networks with laypersons were the most important type of support (Hildingh & Fridlund, 1997). However, knowledge is limited regarding the effect of contact between people suffering from an AMI. Evidence suggests that this type of social support is valuable and that the need for fellowship with others increases post-AMI and through the month after the AMI

((Hildingh & Fridlund, 1997; Pagé, Kovacs, & Irvine, 2012; Steen Isaksen & Gjengedal, 2006).

### ***Peer mentors***

Being a mentor does not imply only to possess concrete knowledge, but in addition, it means to develop a relationship between a person with experience and someone with no, or less, experience (Bozeman & Feeney, 2008). Peer support is a way to encourage compliance with, for example, exercising during cardiac rehabilitation (Worcester & Le Grande, 2008). The peer mentoring used in organisations is a relationship between people with the same interests, i.e., a form of networking (Holbeche, 1996). An increased number of articles describe peer mentoring between people with the same diseases. One example was mentees with early inflammatory arthritis paired with trained peer mentors diagnosed with the same disease. The mentors had the advantage of mentoring and appreciated the education, and the mentees indicated that they had received information and emotional support from the mentors (Sandhu et al., 2014).

## **Theoretical framework**

### **Human Becoming**

The theoretic framework of Rosemarie Rizzo Parse's nursing theory was previously known as follows: Man-Living-Health – A Theory of Nursing (Parse, 1981). The name was changed to Human Becoming to avoid confusing 'man' with 'male' (Parse, 1992) and incorporating *humanbecoming* into one word (Parse, 2007). My choice is to use the name Human Becoming. Parse has written many books and articles about how the theory is meant to be applied in different situations and contexts, and it is impossible to describe everything here. My choice is to focus on aspects of her theory that fit the result of this thesis.

*"The purpose of the method is to uncover the structure of lived experiences with persons or groups who can articulate the meaning of an experience" (Parse, 1992, p 41).*

The fundamental tenet of Human Becoming is described in assumptions, principles, concepts and theoretical structures (Parse, 1981). The theory is interesting and has content that differs from other theories. Furthermore, the primary version has been described primarily with complicated language. In a second updated version, even the language of the assumptions and principles was changed, but the meaning of the theory of nursing itself was not changed (Parse, 1987, 1992). Parse emphasises that science is a dynamic process that suggests the development of new concepts and models. Nursing is a shared focus on 'man and human' with other disciplines, for example medicine, sociology and psychology.

However, the inquiries differ between these disciplines, but the overlap may result in a deeper understanding of health. Human Becoming develops the meaning of the concepts human being, health and the environment, with a focus on the total experience of health. The intention of the theory is to avoid coupling nursing to medicine closely, but instead to develop a paradigm that is related to human science (Parse, 1981).

The nursing paradigm is that the human becoming 'co-participates' with the environment, but 'nursing' is not dividing into the traditional parts; man, health, environment and nursing (Parse, 1981). Parse asserts that the nursing process, assessing, planning, implementing and evaluating, which is usually explained in the nursing discipline, not is grounded in ontology. However, Human Becoming has an origin in ontology for both research and practice (Parse, 1987; 1992). Early descriptions of the theory declared its development from the concepts of Martha E Rogers, which in turn are grounded in existential-phenomenological thoughts. Rogers together with the philosophers Heidegger, Merleau-Ponthy and Sartre inspired Parse in her work to develop her nursing theory (Parse, 1981; 1987). Human Becoming has been described to be related to varying situations, among others, as a mentoring model. Parse explains the application to mentorship from the human-becoming perspective, which is described as a 'moment to moment' relation. Specific Assumptions, Essences and Processes suitable for the model are described (Parse, 2008a) but not mentioned herein.

To be a human implies to have the freedom to choose *how* to be. Originally, the Human Becoming standed of nine assumptions and three principles that include fundamental concepts. Those nine primary assumptions (Parse 1981) were later summarised into three assumptions, which were presented in 1987.

A short summary of the assumptions follows:

**The first assumption** explains that to become a human involve choosing the implied by a situation. This creates an interchangeable process with others and the environment. The meaning of an event for one person could differ from another persons' experience.

**The second assumption** describes an ongoing relationship between a person and the environment that reflects an exchange.

**The third assumption** focuses on the multi-dimensionally movement that occurs in the relationship between the individual and the environment. The possibilities implied by a situation (or an event) will be selected by each person. Parse indicates that this assumption reflects the ontology of Human Becoming, which is to see each person as a whole and not a sum of the parts. She emphasises that every person has a responsibility to choose the meaning in a given situation, which in turn creates health (Parse, 1987).

The fundamental idea of the assumptions is explained below:

*“Three major themes emerge from these philosophical assumptions: meaning, rhythmicity, and cotranscendence. Each leads to a principle of Man-Living-Health.” (Parse, 1987, p 163).*

These principles, which were created from the assumptions, have been elucidated in plain terms and with fewer words in the newer version. The concepts that occur in the principles are grounded in the assumptions described above (Parse, 1987).

The principles are summarised as follow:

**The first principle** contains the concepts ‘imaging, valuing and languaging’. This means that everything in the environment influences the meaning of a situation, i.e., experience of health expressed in ‘speaking and moving’ in everyday life. However, new events influence the meaning of the every day, i.e., the ‘ultimate meaning changes’.

**The second principle** reflects rhythmicity through the concepts ‘revealing-concealing, enabling-limiting and connecting-separating’. This means that an interchanging process is occurring between man and the environment, both with other people and with the surroundings. Every value implies both possibilities and limitations that are not always obvious.

**The third principle** indicates cooperation between the concepts ‘powering, originating and transforming’. This principle explains that because people constantly change, they are transformed to someone they had not been previously. They bear the stamp of relationships with others and what has happened, and this creates a unique human being. 'To power is natural', which I have interpreted as having capacity (Parse, 1981).

The practice methodology in Human Becoming is as follows:

*“The goal in the practice methodology of the theory of Man-Living-Health is in the quality of life as perceived by the person and the family” (Parse, 1987, p 167).*

Three dimensions and three processes containing concepts from the assumptions and principles are summarised (Parse, 1987, 1992). In a revised version, there are also examples of the practice application with the request *“not to make judgments about or label people’s ways of being, thinking, or feeling”* (Parse, 1992, p 40).

‘Cause and effect’ is central to the theory with a focus on well-being and with the relationships as processes. Human Becoming still reflects what creates ‘man-living-health’. Regarding the language with its (ing-)endings, Parse indicates that this usage shows that the concepts are less static. Peoples’ experiences are connected

with the meaning of life, and their own health is affected by their own values. New experiences and meaning in the now influence a new situation that is either the same or different compared with a previous situation. Every person lives in his own way, which can be the same or different from others, which shows that he or she is becoming in his or her own way (Parse, 1992).

Traditionally, for example, pamphlets are provided as information, and all patients receive the same information without consideration of their individual needs (Parse, 1992, 1999). When the Human Becoming practice is used, there are no standardised plans for people who are affected with a disease. However, in addition, nurses should not consider the person to have a 'diagnostic label'. According to Parse, the discipline of 'nursing' has changed more and more from being an applied science to, in practice, becoming a basic science. She emphasises the importance of documentation in nursing, which should be grounded in the individual view of the situation without a focus on the illness (Parse, 1999). Parse criticises the traditional evidence-based practice, which she indicates has been created by the results of quantitative studies that often focus on health problems. This differs from evidence obtained in nursing that starts with the question 'what is real?' and the answer; 'truth for the moment', which is representative of Human Becoming. In research, evidence should correspond to the individuals' description of the phenomenon, which is studied (Parse, 2008a). In a later work, Parse changed the concept 'quality of life' to 'living quality', which is different because 'living quality' is not measured only at a few occasions. Generating, changing and developing concepts is, according to Parse, necessary when new unique paradigms are evolving, in line with Human Becoming (Parse, 2013).



## **Rationale**

Inner stress in combination with resignation and other risk factors could contribute to having a re-infarct. However, a functional social network could be a protective and preventive factor. For example, supportive self-help groups have been shown to be important during recovery, i.e., to share experiences with one another. Follow-up, rehabilitation and support to individuals afflicted by an AMI could differ between densely and sparsely populated areas. Because in densely populated areas, supportive groups occur, while in sparsely populated areas, it is difficult to arrange due to long distances and the geographic spreading of the afflicted individuals. Therefore, it is a risk to not obtain organised, psychosocial support in such counties, although the Swedish law for health and medical care stipulates that 'the goal for health care is a good health and care under equal conditions for the whole population' (HSL 1982:763).

A longitudinal study describing interventions in the form of social support and longitudinal follow-up would provide a perspective on the circumstances of those living in sparsely populated counties. It was of interest to investigate whether the relationship between someone previously afflicted and a person newly afflicted with an AMI would be valuable for both individuals. Would a peer mentor fill part of the void in support in sparsely populated counties? To obtain an answer, an intervention was performed. This means that some people are offering something, while others are not (Polit & Beck, 2012). Thus, people who were newly afflicted with an AMI, with or without a peer mentor, were included together with peer mentors.

## **Aim of the thesis**

The overall aim of the thesis was to investigate the experience of having an acute myocardial infarction in newly afflicted persons living in sparsely populated counties, and whether an intervention with peer mentors would provide support by affecting the perception of illness, health related quality of life and everyday life. The aim was also to describe the support of peer mentors from their perspective and what the mentoring meant to them.

### **Specific aims and research questions of the studies were:**

**I.** To describe individuals' perceptions of the psychosocial consequences of an acute myocardial infarction (AMI) and of their access to support one year after the event.

**II.** To investigate whether changes in illness perception and health-related quality of life occur over time after an intervention with peer mentors 1, 6 and 12 months after an acute myocardial infarction, compared to a group without mentoring. The research questions were the following: 1) Are there any differences in illness perception between the groups and over time? 2) Are there any differences in health-related quality of life between the groups and over time?

**III.** To describe individual perceptions of their lifestyle and support, 1 year after an AMI, with or without mentorship.

**IV.** To describe the personal meaning of being a peer mentor for a person recovering from an acute myocardial infarction. The following issues were explored: 1. How have they experienced the commitment as peer mentors? 2. Do the peer mentors have changed parts of their own Illness Perceptions after one year of mentoring others? 3. Have their Physical and Mental components scores changed during the year as a mentor?

## METHODS

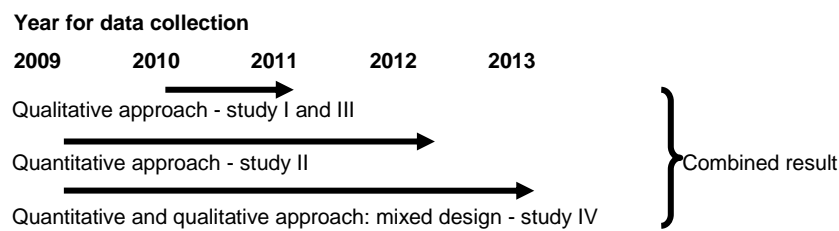
### Design

The present thesis has a prospective, longitudinal, quasi-experimental, comparative design. The thesis comprises four studies (Table 1) that focus on the opportunity to engage peer mentors to support people who are newly afflicted with a first AMI during the first year of recovery. Three of the studies (**I, II and III**) included newly afflicted persons consisting of participants with or without peer mentors. Study **IV** included the peer mentors, who personified the intervention.

**Table 1. An overview of the studies**

Paper	Aim	Design	Data collection	Sample	Analysis	Status
I	To describe individuals' perceptions of the psychosocial consequences of an acute myocardial infarction (AMI) and of their access to support one year after the event	Qualitative	Individual interviews	20: 11 with mentor 9 without mentor	Qualitative content analysis	Published
II	To investigate whether changes in illness perception and health-related quality of life occur over time after an intervention with peer mentors 1, 6 and 12 months after an acute myocardial infarction, compared to a group without mentoring.	Longitudinal Quantitative	SF-36 IPQ-R	62: 28 with mentor 34 without mentor	Descriptive statistics and Two-way ANOVA for mixed design and One-way repeated-measures ANOVA with <i>post hoc</i> tests	Submitted
III	To describe individual perceptions of their lifestyle and support, 1 year after an AMI, with or without mentorship	Qualitative	Individual interviews	20: 11 with mentor 9 without mentor	Qualitative content analysis	Published
IV	To describe the personal meaning of being a peer mentor for a person recovering from an acute myocardial infarction.	Mixed design	SF-36 IPQ-R  Individual interviews	22 peer mentors  15 peer mentors	Paired-sample <i>t</i> -test  Qualitative content analysis	Submitted

To obtain results, both inductive and deductive research were used: inductive means that patterns of interrelationships arise from the data, for example, based on interviews; while deductive means that the data are generated from predetermined dimensions, for example, based on questionnaires (Patton, 2002). In addition to three participant groups, the thesis included both quantitative and qualitative studies to show the phenomenon from a greater number of perspectives (Figure 1). Study I and III had a qualitative design, while study II had a quantitative, prospective and a longitudinal design. Study IV, which included peer mentors, had a mixed design, i.e., integrating both quantitative and qualitative data. One reason to use mixed methods is that one of the methods could follow-up the other one and thus complement the data (Curry, Nembhard, & Bradley, 2009). According to Morse (2012, p 554), a mixed method design has a complete part and an incomplete part, with the latter used for complementation and insufficient for separate publication. The outcomes were physical, psychological and social fields, which show psychosocial consequences, illness perception, HRQoL, lifestyle and importance of support.



**Figure 1. Integrated interpretation of the four studies: Combined result**

### Study Context

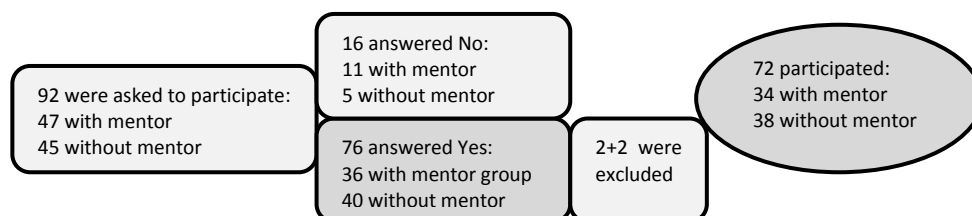
The study context of this thesis was to gain the unique perspectives of the participants of having an AMI and living in sparsely populated and/or rural areas in central/northern Sweden. The counties average number of inhabitants per square kilometre was 2.6, 9.9 and 11.2 (Statistiska Centralbyrån [SCB], 2013). A sparsely populated area has definitions that vary between different organisations, but the most applied in Sweden is as follows: > 45 minutes car journey to the nearest densely populated area with more than 3000 inhabitants (Glesbygdsverket, 2007; Tillväxtanalys, 2011). A rural area is (in Swedish perspectives) a term that describes the countryside with a population density of  $\geq 5$  inhabitants per square kilometre, while a sparsely rural area has a population density of  $\leq 5$  inhabitants per square kilometre (Jordbruksverket, 2013). The newly afflicted participants in this thesis lived from 0 to 180 kilometres to the nearest hospital.

## Setting

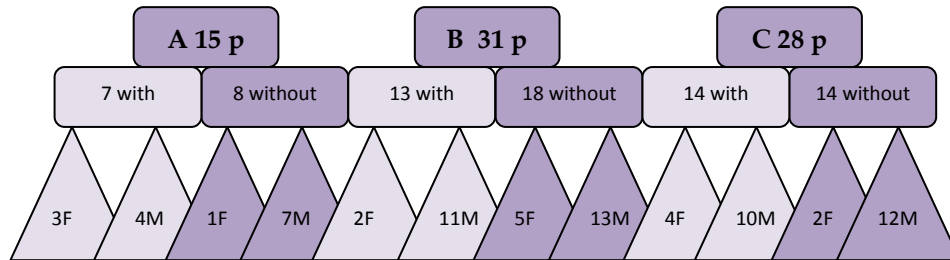
The participants who were newly afflicted with an AMI were recruited from three hospitals (A, B and C) in towns located in municipalities with between 20 115 and 60 000 inhabitants. All of the contributing hospitals have a CCU, but none of the hospitals offered invasive procedures such as percutaneous coronary intervention (PCI) or coronary artery bypass grafting (CABG). Patients who needed such treatments had to be transported to a larger hospital. Subsequently, they returned for care at the CCU at their 'home hospital' or, in some cases, to their homes. Hospital A had 416 beds: 23 at the CCU, six intensive-care beds and 17 beds for ambulatory patients. Hospital B had 170 beds. Patients with an AMI received care at the ICU in the acute phase. Later, they are transferred to a 27-bed general medical unit that was largely for patients with stroke or AMI. Hospital C had 102 beds, 18 of which were at the CCU. The number of beds was valid at the moment the studies were conducted.

## Participants

*The inclusion criteria for participants newly afflicted with an AMI were as follows:* Men and women suffering from an AMI for the first time, <75 years old and cared for at a CCU with AMI as the main diagnosis. The patients were able to speak and understand Swedish, spoken and written, to complete the questionnaires in a reliable way. They should not have any known psychiatric diagnosis, including dementia; individuals with a psychiatric diagnosis were excluded to eliminate the risk of confounding factors. In addition, patients were excluded if they were > 75 years old or had been afflicted with an AMI previously. Ninety-two people conformed to the inclusion criteria and were invited to participate in the project. Seventy-four men and women (80%) accepted; 34 (25 men and 9 women) were offered peer mentors and 40 (32 men and 8 women) were not (Figure 2). Some of the participants lived in larger communities or cities, but most of them lived in the countryside. The distribution of participants in the three hospitals is presented (Figure 3). My choice is to call them 'newly afflicted' despite it being one year after the AMI.



**Figure 2. Distribution of the 92 newly afflicted individuals who accepted to be contacted as well as the dropouts and continued participation of the remaining newly afflicted individuals.**



**Figure 3. Distribution of participants with and without mentors from the three hospitals; p= participants, m= male, f= female. Notably, one female from B and one male from C (without mentors) were immediately excluded because they abstained from answering any questionnaire.**

The layman who should act as a peer mentor to people who are newly afflicted with an AMI would be as follows: men and women < 75 years of age and with the experience of an AMI between 1 and 10 years prior, which was considered to be the correct duration of time to act as a peer mentor. Altogether, 52 people expressed interest in mentoring, and 34 people participated because this was the number of participants in the peer mentor group. Participants who contribute to results in the thesis are as follows: with peer mentors (n=28), without mentors (n=33) and peer mentors (n=22/15). The demographics for age, sex, marital status, and education level are shown for all three groups (Table 2).

**Table 2. An overview of the demographics for the included participants at baseline**

Demographics	With mentor N 28 (%)	Without mentor N 33 (%)	Mentor N 22 (%)
<b>Gender</b>			
Male	21 (75)	28 (85)	16 (73)
Female	7 (25)	5 (15)	6 (27)
<b>Age</b>			
≤ 61	12 (43)	16 (48)	6 (27)
≥ 61	16 (57)	17 (52)	16 (73)
<b>Marital status</b>			
Married/Cohabiting	20 (71)	33 (100)	18 (82)
Living alone	8 (29)	–	4 (18)
<b>Employment (baseline)</b>			
Gainfully employed	6 (21)	8 (24)	4 (18)
Siclisted	8 (28)	11 (33)	–
Unemployed	1 (5)	–	1 (5)
Retired	13 (46)	14 (43)	17 (77)
<b>Highest education</b>		No answer = n2	
Compulsory school ≤ 9 year	15 (53)	13 (39)	7 (32)
High school 2-4 years	8 (29)	13 (39)	8 (36)
College / university	5 (18)	5 (15)	7 (32)

## Procedure

Before the hospitals were contacted, ethical approval to conduct the project was received (see 'Ethical considerations'), and written permission was provided by the superiors at the medical clinics. Thereafter, the staff at the coronary care units (CCUs) was informed about the study. Coronary care nurses (CCNs) at the coronary care receptions were likewise informed on two occasions because it was those nurses who would recruit the patients for permission to have their contact details sent to the author. No other information was provided.

*The procedure for the participants who were newly afflicted with an AMI* was as follows: they were recruited according to standard procedures and invited to revisit a CCN at the respective CCU approximately 2 weeks after discharge. At this time, the CCNs asked all of the patients who met the inclusion criteria about permission to send their names, age and telephone number to the author, i.e., a consecutive sampling (Polit & Beck, 2012). When e-mails with contact details were received from those who agreed to be contacted, every other person was divided to receive or not to receive a peer mentor. They were all given a code, and then they were contacted by phone to be informed (oral) about the project and what their participation entailed. After that information was received, they were asked if they would like to participate in the study. Some (n=16, see Figure 2) of the patients who had agreed to being contacted declined to participate for different reasons or for no particular reason. It is notable that they did not have any information about the meaning of the project before they were contacted. Because they already had been given a code, those codes were not used subsequently. There was no control for external influences.

Those who still expressed an interest in participating in the study received an information letter with contact details (e-mail address and phone number), which was sent to my supervisors and myself. They also received a questionnaire as well as some questions about demographics and a pre-addressed envelope. When the questionnaire had been answered and returned, nothing further happened for the participants without mentors until the next questionnaire had to be answered. For participants in the peer mentor group, suitable mentors were selected by matching for sex, age and locality. The mentor would be roughly the same age as the participant ( $\pm 4$  years) and preferably lived in the same village or as close as possible.

*The procedure for recruiting peer mentors* was first, to visit seven local heart and lung associations in the three counties and provide their members with information about the project. Mentors had to be willing to act as a peer mentor to a person

who was newly afflicted with an AMI. Written information on the project and application forms with answer envelopes were left at the locality after the information was provided. Furthermore, advertisements asking for mentors were published several times in the local press and in free newspapers (distributed to all households in a district). Some interested individuals responded by phone and received at that time the first oral information about the project. Those who remained interested received a letter containing written information and the e-mail addresses and phone numbers of the authors. Others who were interested in learning more about the project sent an application form that was mediated by the heart and lung associations. Those individuals were phoned to provide oral information about the project.

### **Intervention**

As soon as a newly afflicted who would be offered a mentor agreed to participate in the study, a suitable mentor was contacted. If the mentor was still interested in continuing, he/she received questionnaires and some questions about demographic details. After the questionnaire had been answered and returned by both the peer mentor and the newly afflicted participant, the author phoned the mentor to inform him/her of the mentee's name and phone number. In each contact with all participants, they were informed that they were welcome to contact the author with any thoughts they wanted to share or questions they needed to ask. The peer mentors received carefully worded information stating that their participation would not in any way be therapeutic and that it was not necessary that their conversations deal with AMIs. They received repeated instructions that their role was to be that of a fellow human and were advised to think of the newly afflicted AMI sufferer as a new neighbour they were getting to know.

### **Data collection**

Data collection included self-reported questionnaires and individual interviews. A questionnaire was sent to the newly afflicted participants on three occasions during the year: approximately two to three weeks after their discharge from the hospital = baseline, six months, and one year after their AMI. A questionnaire was sent to the peer mentors on two occasions during the year: at the baseline mentioned above and after one year. If the participants did not answer the questionnaire within two weeks, a reminder was sent in the form of a letter. This process was repeated with a letter and with new questionnaires approximately two weeks later but no later than that. Data collection in the form of questionnaires took place from August 2009 to May 2012 with all participants (**II, IV**): those with mentors (n=28), without mentors (n=33) and with peer mentors (n=22). Data collection through interviews with participants (n=20) with or without mentors



was conducted between August 2010 and April 2011 (I, III) and with peer mentors (n=15) during autumn 2013 (IV).

### **Questionnaires**

Study II had a quantitative approach that consisted of a questionnaire: Revised Illness Perception Questionnaire (IPQ-R) and The Short Form 36 Health Survey<sup>1</sup> (SF-36). When conducting a quantitative study, an author must ask him- or herself whether the level of evidence is sufficiently high. The most important criteria are that the instruments have a high validity and reliability (see below) and the statistical calculations that are used (Polit & Beck, 2012, p 331, 336).

#### ***Revised Illness Perception Questionnaire (IPQ-R)***

One instrument was the IPQ-R, which has the goal of helping the respondents quantify their own perceptions of their illness (Moss-Morris *et al.*, 2002). There are no special requirements for using the IPQ-R instrument; however, there are some reservations to using it. The questionnaire was developed from a forerunner, the Illness Perception Questionnaire (IPQ). The first revised version, IPQ-R, was developed to strengthen the reliability of the instrument (Moss-Morris *et al.*, 2002), and it was translated into Swedish. The translated version has been used in the studies in this thesis (Alsén *et al.* 2010b). The Swedish version of IPQ-R has undergone strict validation before (Weinman, Petrie, Moss-Morris, & Horna, 1996) and after (Alsén *et al.*, 2010b) the translation. The validation process included persons recovering from an AMI (Brink, Alsén & Cliffordson, 2011).

The IPQ-R is divided into three sections. The first section consists of 14 statements about symptoms (Identity scale), which are presented in two columns with the following statements: 'Those symptoms have occurred after the illness' and 'Those symptoms are related to the illness', and answered with 'yes' or 'no'. The numbers of 'yes' responses in the second column are subsequently summarised. A greater number of 'yes' responses indicate that more responses are interpreted as a strong perception that the symptoms are related to the illness. Section two and three consist of 56 items. The second section is named 'Perception of illness' (38 items), and the third section is called 'Cause of illness' (18 items). The answer options are provided on a five-point Likert scale. Several items in the second section must be reversed, and then the items are grouped into 7 dimensions by building indexes. High scores in the dimensions Timeline acute/chronic (a perception of how long the illness will last, 6 items), Timeline cyclical (4 items) and Consequences (6 items) are interpreted as a strong belief that they negatively impact the illness together with Identity. High scores in the remaining four dimensions are interpreted as personal control and insight regarding how the illness affects the individual and, consequently, represent positive beliefs: Personal control (6 items), Treatment

control (5 items), Illness coherence (5 items) and Emotional representations (6 items). The third section consists of 18 items for Cause of illness that should be analysed separately, but this section has not been used in any of the studies.

### ***Short Form 36 Health Survey1 (SF-36)***

SF-36 is a widely used health instrument to measure physical and psychological health with regard to HRQoL and is standardised within the scope of the International Quality Of Life Assessment (IQOLA) (Aaronson et al., 1992). Permission to use the SF-36 was obtained from OptumInsight under the following license numbers: QM 018370 (II) and QM 020643 (IV).

SF-36 is frequently used, both within and outside of Sweden, and has been validated (Persson, Karlsson, Bengtsson, Steen & Sullivan, 1998). The Swedish version of SF-36 was standardised using Swedish norms in seven population studies (Sullivan, Karlsson & Ware Jr, 1995) and has cross-cultural stability (Sullivan & Karlsson, 1998; Persson et al., 1998). SF-36 is appropriate for studying changes over time and when repeated or comparative measures are used. The questionnaire comprises 35 items that are grouped into 8 multi-item scales that concern function and well-being. The functional scales are as follows: Physical Function (PF, 10 items); Role function Physical causes (RP, 4 items); Role function Emotional causes (RE, 3 items); Social Function (SF, 2 items) and Bodily Pain (BP, 2 items). The Well-being scales are as follows: Mental Health (MH, 5 items); Vitality (VT, 4 items) and General Health (GH, 5 items). There is also one question about change in Health (Health time = HT) compared to one year prior. The items are scored from 1-2, 1-3, 1-5 and 1-6.

Several scores must be reversed before the analysis, and the multi-items scales must be transformed to a scale from 0-100; this process allows the answers to consist of corresponding levels (Sullivan, Karlsson & Taft, 2002). In general, larger scores indicate higher levels of health status. It is also possible to develop two health indexes as two overall dimensions of the multi-item scales: Physical health (PCS) includes PF, RP, BP and GH; and Psychological health (MCS) includes VT, SF, RE and MH (Sullivan et al., 2002).

### ***Reliability***

#### ***Cronbach's Alpha***

To determine whether the mentioned indexes had internal consistency, Cronbach's alpha was conducted for the dimensions (IPQ-R) and multi-item scales (SF-36). It reflects whether an index is reliable, which means that the value should be >0.7 (Barmark, 2009). In IPQ-R (II), the Chronbach's  $\alpha$  coefficient varied between the measures as follows: Timeline acute/chronic:  $\alpha=0.886-0.896$ ; Timeline cyclical:  $\alpha=0.667-0.862$ ; Consequences:  $\alpha=0.702-0.766$ ; Treatment control:  $\alpha=0.649-0.769$ ;

Illness coherence:  $\alpha=0.780-0.902$ ; Emotional representations:  $\alpha=0.830-0.910$ ; and Personal control:  $\alpha=0.422-0.657$ . Two of the dimensions were analysed (IV): Illness perception with a Chronbach's  $\alpha$  coefficient at baseline of  $\alpha=0.670$  and after one year of  $\alpha=0.931$ , while Emotional representation had the same value at both measurements of  $\alpha=0.779$ .

The Chronbach's  $\alpha$  coefficient in SF-36 (II) achieved the following variations: GH:  $\alpha=0.774-0.832$ ; BP:  $\alpha=0.935-0.949$ ; VT:  $\alpha=0.806-0.870$ ; SF:  $\alpha=0.697-0.915$ ; MH:  $\alpha=0.848-0.912$ ; PF:  $\alpha=0.891-0.929$ ; RP:  $\alpha=0.834-0.902$ ; and RE:  $\alpha=0.820-0.875$ . In SF-36, the Chronbach's  $\alpha$  (IV) for PCS measured at baseline and after one year was  $\alpha=0.661$  and  $\alpha=0.772$ , respectively, while MCS at baseline had a Chronbach's  $\alpha$  of  $\alpha=0.752$  and, on a second occasion, of  $\alpha=0.827$ .

## Interviews

In study I and III, individual interviews with the newly afflicted participants with or without mentors were conducted. The newly afflicted participants who first reached one year after their AMI were asked to participate in an interview. All of those with peer mentors who were asked agreed to be interviewed. Four out of them without mentors declined, while the remaining who was asked agreed to be interviewed. The interviews included 20 participants with peer mentors ( $n=11$ ) and without mentors ( $n=9$ ). Digitally recorded interviews (18 face-to-face and two phone interviews) were performed one year after the AMI. The interviews took place in the homes of the participants or at a university (exclusively phone interviews) depending on the desires of the participant. The purpose of the interview was explained to the person before it took place, and informed consent was received. The participants were informed about confidentiality (it would not be possible to recognise the individuals in the study) and their right to withdraw without any explanation. Furthermore, the participants were informed that field-notes would be performed during the interview; if something was unclear, it should be questioned later such that the narrations were not disturbed.

The interviews completed in these studies were partly semi-structured, and an interview guide was used that consisted of subject fields (Kvale & Brinkman, 2009, p 19) that were interesting for the purposes of the thesis. The interviews started with a dialogue between the author and the participant, which is an effective way of creating a relationship between the involved persons (Munhall, 2012 p 50-51). The same opening question was asked in all of the interviews: *How do you feel today?* The subject fields were as follows: The year after the AMI; State of health; Support; Meaning of life; Lifestyle. Questions were formulated carefully, preferably beginning with *what* and *how* (Kvale & Brinkman, 2009 p 129). The participants were queried whether they had additional information to provide and were asked if they could be phoned if something was unclear. They were then given a phone

number to contact the authors if they had something more to relate or to ask, or even if they regretted their participation. The interviews lasted between 20 and 56 (mean 36) minutes, with an average of 34 minutes, for participants with peer mentors compared with 39.5 minutes for those without mentors.

Interviews in study **IV** were conducted later than the other interviews. After the project had been completed, a letter was sent to all of the peer mentors to determine whether they would like to participate in a telephone interview. The focus was to let them relay their experience of being a peer mentor. Telephone interviews suggest that the informant is relaxed and more willing to talk (Novick, 2008). Fifteen of the participants reported their interest in participating soon after they received the letter. No further letters were sent because the interview material was judged sufficient. Before the interviews, the participants were reminded about the purpose of the interview. The interviews were digitally recorded, as informed in the letter. The interviews were semi-structured, and a guide was used for a few question areas (Kvale & Brinkman, 2009 p; Patton, 2002, p); for example, 'What have being a mentor meant to you?', 'How should a mentor be prepared?' Clarifying questions could include the following: 'Could you provide an example?' or 'What do you mean?'.

## **Analysis**

### **Quantitative analysis**

In study **II**, the SPSS computer program (SPSS 20.0 Statistics, IBM, New York, US) was used for the statistical analysis, which was performed for the dimensions (IPQ-R), multi-item scales and health indexes (SF-36). Descriptive data in the form of mean values enabled us to compare the data with Swedish populations for the IPQ-R (Brink et al., 2011) and the SF-36 (Sullivan et al., 2002). To investigate whether the intervention had an impact on the groups and over time, two-way analysis of variance (ANOVA) for mixed designs was used. The factors (independent variables) were groups and time, whereas the dependent variables were dimensions (IPQ-R) and subscales (SF-36). It was predetermined that if significant differences ( $p \leq 0.05$ ) were found between the groups and time-points (1-2, 1-3 and 2-3), a one-way repeated-measures ANOVA with *post hoc* tests (Bonferroni comparisons) would be performed to evaluate the differences (Hassmén & Koivula, 1996). This type of analysis is applicable when similar groups are repeatedly tested. All of the analyses assumed a significance level ( $p$ ) of 0.05.

In study **IV**, the two dimensions of interests in the IPQ-R and the two health indexes in SF-36 were analysed using SPSS (SPSS 20.0 statistics, IBM, New York, US). Descriptive data are presented as frequencies. Based on the answers to IPQ-R, a paired-sample *t*-test was conducted on the dimensions Illness Coherence and

Emotional representation. This was performed to study whether the mentors' answers had changed over the year. In addition, in SF-36, a paired-sample *t*-test was suitable to evaluate whether the results obtained for PCS and MCS had changed during the assignment. Analyses which valued ( $p$ ) < 0.05 were considered statistically significant.

### Qualitative analysis

The recorded interviews (I, III, IV) were transcribed verbatim soon after the interviews. Content analysis was aimed to identify patterns and themes, and the analysis was carefully performed to ensure consistency with the text. This strategy is consistent with that described by Long and Johnson (2000), who described the importance of ensuring reliability. The texts were then worked through step by step using qualitative content analysis, a process described by Graneheim and Lundman (2004). Content analysis is appropriate for studies with a qualitative descriptive design (Sandelowski, 2000). Such an analysis is systematic and therefore replicable, according to Krippendorff (2013). After transcription, the interviews were read several times to obtain a sense of their content. Next, they were structured by identifying meaning units comprising one or several sentences, depending on the contents, and guided by the aims of the studies. In the next step, each meaning unit was condensed to a shorter form and labelled with a code. The codes were sorted into sub-themes based on similarities, and examples are presented (Table 3). The interpretation process involved moving back and forth between the steps described above and taking a dialectic approach to the whole and parts of the texts. This process is difficult to describe because any description makes the method appear more linear than it is.

**Table 3. Examples of content analysis that was accomplished in study 1 and 3**

Meaning unit	Condensed meaning unit	Code	Subtheme	Theme
<b>Study 1:</b> <i>My mentor do not intrudes on me, but he seems to be able to read me, when he. . .when he needs "go into" with his support</i>	My mentor know when I need his support	My mentor know	To have support from a mentor	Having access to support
<b>Study 3:</b> <i>During the first period I was a little afraid of lifting ... since I had been told 'you must not lift'. But now I feel that I also have learned this part. I do not lift anything unless I need to. I've also learned with the tractor ... that I'm using the tractor more than before</i>	I was afraid of lifting but now I use the tractor to a higher extent	Physical limitation	To have bodily limits	Being in an afflicted body

## **Ethical considerations**

It is important to always take ethical considerations into account when people in an exposed situation are involved in research. Approval to perform the studies was received from the Regional Ethical Committee at the Medical Faculty at Umeå University (15 May 2009: Dnr 09-100M). All of the planning content and all of the procedures followed in the studies of this thesis work conformed to the principles outlined in the Declaration of Helsinki (1964). In accordance with the Code of Ethics for Nurses (International Council of Nurses [ICN], 2012), the participants were met with respect for them as individuals and in unity with human rights. It is essential that every study participant is fully informed about the project to ensure participant confidence and motivation. The participants received both oral and written information about the aim of the project and the details of participation. All of them were informed that participation would be voluntary with the right to withdraw whenever they wanted without needing to provide an explanation. They were also assured of the confidentiality of the study (it is not possible to identify individuals in the results). All of the participants have been offered contact with the authors at any time should any undesired situation or thoughts relating to the study or their illness arise. In addition to the typical information, the participants without mentors were carefully informed that other participants were offered peer mentors.

## RESULTS

The four studies were interpreted in an integrative manner: there were similarities and differences between the newly afflicted participants. The results of the thesis were obtained from the perceived consequences and meaning of support (I) through perceptions of illness and HRQoL (II) and how life-style and support were experienced during the first year after an AMI (III). Consequently, because there were both participants who received a peer mentor and those who did not, a comparative approach was used. Accordingly, the perspectives of the peer mentors of their commitment were interesting, and if something had changed in the quantitative part (IV). This technique resulted in the presentation of integrated results and a simple overview of their association (Figure 4).

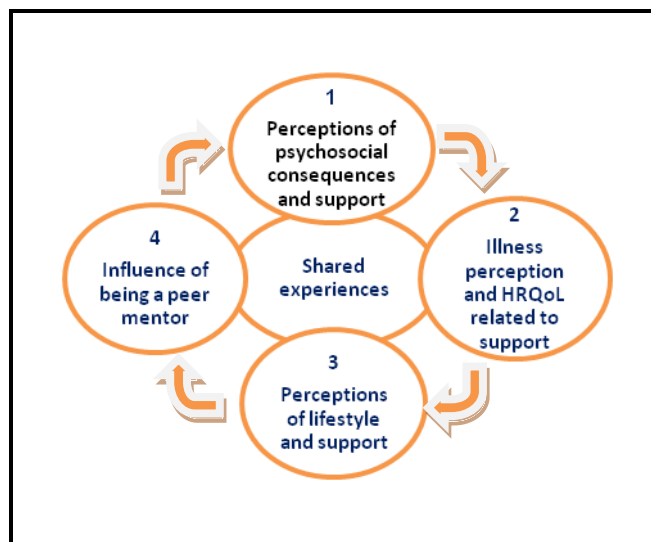


Figure 4. A symbolic view of the relationships between the four studies. The arrows indicate a never-ending cycle, implying that the recovery and insights of the participants developed irrespectively of their roles and when their AMI had occurred.

## Drop-outs

Of the 92 newly afflicted participants who were asked to participate in the study, 16 declined (11 had been allocated to have a peer mentor, and 5 were without a mentor). Furthermore, two of the participants who were allocated to those who were offered mentors had a re-infarction, i.e., 13 dropped out. Two of them without mentors did not respond to any questionnaire (one female and one male); those did not contribute to the results at all: they were considered as drop-outs that included 7 participants without mentors (Figure 2).

All of the 34 (100%) participants with peer mentors completed and returned the questionnaires at baseline; 32 answered the questionnaires six months after their AMI (91%) and 29 (88%) after one year. The number of participants with mentors who answered the questionnaires at all three measurements was 28 (85%). There were 38 (95%) without mentors who returned the questionnaires at baseline and 36 (90%) at the second measurement, while 36 (90%) answered the questionnaires after one year. The number of participants without mentors who answered the questionnaires at all three measuring was 33 (82,5%).

One presumptive mentor was not considered to act as a mentor because this person was diagnosed with heart disease other than AMI. Furthermore, 3 who had declared their willingness to be a mentor were unable to assume the role due to a health problem when the mentee was available. One of them had already started mentoring, and the mentee was offered and accepted a new mentor. All 34 (100%) answered the questionnaires on the first occasion, and 22 (65%) sent them back on the second occasion.

## The meaning of becoming a person with an AMI

One year after their AMI, the newly afflicted participants mostly achieved an acceptance of their existence and their situation: there were narratives about gradually achieving an awareness of their condition (I). However, they had, in some cases, returned to the hospital with chest pain because they had been informed that a second AMI could show symptoms other than the first one (III). Some participants indicated that the first year was a tough experience with hesitation to make future plans. They did declare that it was essential to reach one year after the event, which had been a goal (I).

*“Maybe it is pretty good anyway, but it has been dearly bought. Perhaps I have learned something, but it have been a tough adjustment I must say (...) It was quite hard the first six, seven months” (male without mentor)*



Among those without mentors, negative thoughts existed one year after the AMI, but nevertheless, there were tendencies to ignore that they had gone through an AMI (I). Others were more spontaneous, and they listened more to what they really wanted to do (III). There was also an opinion that the AMI had been a positive experience, providing a new perspective on life. They were thankful for their everyday life and had changed their mind about what was important to them (I). Scales measuring well-being in the SF-36 did not differ as much between the newly afflicted, although those with peer mentors showed higher mean values after one year. Furthermore, there were significant variances in time for participants in two of the three scales measuring well-being (II).

### **View on health care**

Participants had mostly similar opinions about how their follow-up functioned during their recovery. They appreciated the CCNs, from whom they had received good information in relation to discharge and at their first follow-up. The most satisfied participants were those who had participated in medical research because it provided open access to the CCU. However, in general they requested more follow-up and support from the CCUs, and they were also dissatisfied with what they expressed as 'impersonal information'. One example was that no one had told them about the psychological consequences that could occur. There was also an uncertainty about who had responsibility for them, i.e., the CCU or open health care, which contributed to their insecurity. Participants with a need for help to perform life-style changes, for example, dietary changes, had not received assistance (I).

### **Consequences**

In the dimension Consequences (IPQ-R), those without a mentor had larger mean values at the three measurements, which indicated more negative consequences from the illness. Accordingly, two-way repeated ANOVA revealed significant effects between groups. Furthermore there were significant variances for time. Both results were confirmed using between-groups ANOVA with dependent measures and the *post-hoc* Bonferroni comparison. There was also a significant variance between those with and without mentors in terms of how long they thought their illness would last, i.e., in the dimension Timeline acute/chronic (IPQ-R) had higher mean values for those without mentors. There was also a significant effect of time (without defining if they had a mentor or not) in this dimension, as confirmed using *post-hoc* Bonferroni comparisons (II).

### **Physical consequences**

The most frequent symptoms in all participants, according to the Identity scale in IPQ-R, were decreased physical capacity and fatigue. Furthermore, breathlessness occurred in those who were newly afflicted, and shortness of breath also occurred in the mentors. In most cases, the symptoms decreased over the year (II, IV). However, those without a mentor showed a greater proportion of the symptoms than those with peer mentors, excluding a few occasions. They also reduced their symptoms to a lesser extent than those with mentors (II). The newly afflicted experienced physical restrictions due to weakness after discharge from the hospital, and sometimes, they blamed their medication. Unexpectedly, there were new sensitivities to warm or cold weather, which in some cases limited outdoor activities (III). The participants also expressed some physical changes that were difficult to interpret (I). Nevertheless, for most, physical strength returned stepwise over time, and some participants even felt stronger after than before their AMI. Such positive differences were especially expressed by those who had stopped smoking (III).

### **Psychological consequences**

The newly afflicted participants expressed that after discharge, they had experienced feelings of euphoria. However, the weakness following the AMI affected their energy and sometimes contributed to feelings of hopelessness during recovery. Other feelings that occurred were inner anxiety, which was sometimes difficult to master with unlimited worry. There were confessions concerning the fear of dying, meaning not living a long life. Sometimes, the participants experienced a fear of having a second AMI one year after the event. Psychological reactions surprised them and sometimes led to feelings of lost control (I). Participants without mentors felt loneliness and difficulty managing their condition because being alone was associated with dark, frightening thoughts and existential brooding (III). According to the peer mentors, worry and ponderings after an AMI are not unusual, and their opinion was that such reactions should be supported. They had experienced such feelings themselves and had wished to have contact with someone with the same experiences after their AMI (IV). However, the anxiety that occurred in the newly afflicted participants decreased over time, and most individuals were satisfied with their recovery. One-year survival after an AMI contributed to their belief in the future (I). A new awareness did result in really 'being' in, for example, early mornings. Another positive consequence was that life had a deeper meaning, and they had received insight to listen to their own needs more than before the AMI (III).

## Everyday life

Everyday life was influenced by the AMI for most of the newly afflicted participants in different ways. The worry of having a second AMI resulted in the fear of physical activities, and for some of them, it meant to ensure they were near health care facilities (I).

*“We would travel abroad and I did sit down with the damn map (...) I had to looking forward and plan and would tick off every hospital (...) I did not say anything but had to fiddle (...) When we went to a restaurant in another place I had to look at the map again to know exactly where the nearest hospital was located. I was quite paranoid” (Female with mentor)*

Fear occurred concerning activities during recovery, which in addition to causing physical limitation restricted their social life (I). However, most of the participants wished for their previous everyday life back, to continue their earlier lifestyle without changes (III). For the most part, they were satisfied with an everyday functioning life one year after the AMI (I). Positive insights led to participation in fun events with friends and joy in life (III).

## Life-style

Some participants saw the AMI as a turning point; changes in their life-style had been necessary, for example, physical exercise was a new experience for some of them. However, a greater number of participants who had changed some habits after discharge from the hospital, returned to their old life-style. According to those participants, exercising was boring, indicating that the suggested changes had a negative influence on their everyday life. Others, who had been exercising at a high level before their AMI, had given up this routine without medical restrictions. Overall, most of the participants performed the same physical and social activities as they had performed before the AMI. For example, hunters began to hunt again despite the risk of excitement. All of the mentees who had been smokers before the AMI had quit; they would not allow bad habits to further affect their health. Not everyone without mentors had been able to quit, or they had stopped smoking for a while and then started again. However, there were participants who lived a healthier life-style than they had before their AMI (III).

## Health

On the whole, for the newly afflicted, an environment with the possibility of being in nature or to living in the countryside meant a lot, which was expressed as a definition of quality of life (III). In the SF-36, in the health index measuring psychological health, MCS, the participants showed a large increase in values from

baseline to the measurement after one year (II). The opposite was shown for the peer mentors because they had decreased their mean values in MCS during the year; however, the values were not significant according to a paired-sample *t*-test (IV). The health index PCS showed equal values for the newly afflicted participants after one year. In Health Time (SF-36), those without mentors praised their health to a somewhat higher degree compared to one year prior (larger scores indicates a higher level of health status) than those with peer mentors. However, all of the participants displayed strongly decreased mean values over time, furthermore confirming the significant variance with time according to a one-way ANOVA for a mixed design (II)

## Meaning of support

The newly afflicted testified that support from their families and relatives, who are encouraging, made them feel secure. People without mentors spoke with other patients, while others did not meet with those who had experienced an AMI. However, some of the participants did not want to talk about the AMI at all (I).

The mentees had waited eagerly for the first phone call from the peer mentor, an experience they shared with the mentors, who had felt excitement before their first contact. A greater number of the mentors and mentees felt that their first contact had been 'easy going', and when the relationships had worked well, it led to a new friendship. They had, for example, accomplished different activities together, and their conversations about AMI were minimal (I, IV). In general, the mentees were satisfied with the relationship with their peer mentors; however, this arrangement did not work for some participants (I). According to the mentors, this was due to different personalities and a lack of personal chemistry, or it just felt 'wrong'. Some of the peer mentors blamed him/herself due to having been too active, while others experienced the mentee as uninterested without the need for contact. For some, long distances resulted in difficulties arranging personal meetings (IV).

However, the newly afflicted individuals had, in most cases, valued participating in the mentor's experiences, which meant a lot (I). This process was also important to the mentors; sharing their experiences gave them positive feelings and confirmation. Being a peer mentor also led to the insights that people could be affected by AMI in different ways. Their commitment contributed to feelings of pride, and for some, even led to an elevated health status. The paired-sample *t*-test revealed significantly increased mean values in the analysis of Illness Coherence and Emotional Representation (IPQ-R) for the peer mentors (IV).

*I feel that this has been good, and I think that the other person has this opinion too, and I have even been happier' (Mentor, male, 70)*

The peer mentors underscored the importance of early contact and meeting personally. According to them, personal chemistry and similar life situations are decisive factors in determining how the relationship will continue. They missed having some type of preparation prior to their commitment, for example, meetings with other peers. Overall, most of them had learned something new and would not hesitate to being a peer mentor again if they were asked (IV).

## **DISCUSSION**

### **Discussion of the results**

The overall aim of the thesis was to investigate the experience of having an acute myocardial infarction in newly afflicted persons living in sparsely populated counties, and whether an intervention with peer mentors would provide support by affecting the perception of illness, health related quality of life and everyday life. The aim was also to describe the support of peer mentors from their perspective and what the mentoring meant to them. Therefore, the studies were grounded in investigations of people with a life threatening issue, with an interest in *if*, and in such cases, *which* consequences they experienced. Another focus was how quality of life was influenced during recovery, just as their life-style. The results were synthesised in terms of the Human Becoming nursing theory, from the perspective explained in the assumptions, themes, principles and concepts (Parse, 1981). Relate to Human Becoming under the circumstances of having had an AMI, there were challenges, but it was helpful to receive a deeper understanding of being a human with an illness that affects everyday life in more than one way. The view of the human being in the results, could be reflected in the Human Becoming nursing theory.

### **Perceptions during the recovery process**

Having an AMI may imply a life process that occurs over time. The process is a form of recovery and an example of undergoing, after a life-threatening event, a change in everyday life with, hopefully, an improved health status. Participants indicated that life had a deeper meaning, which implied they thought of themselves and their own needs more frequently. This finding was consistent with others who indicated that values became more essential to them after an AMI (Baldacchino, 2011). How recovery continues is partly a result of choices, and according to Human Becoming, it is a human being's freedom to choose how to be, which implies unique possibilities (Parse, 1981). How the participants made their choices varied, and it is feasible to draw a parallel with the first assumption of the theory, declaring that an event provides different meanings to different persons (Parse, 1987). One example is to not 'pretend' having an AMI, or another form of

denial; there is unspeakable happiness with having survived. Such feelings changed during the recovery, and with time, they grew into a fear of dying and feelings of solitude. A more detailed interpretation of the perspective of Human Becoming could be as follows: because an individual can be changed, the participants were 'transformed' into being another person than they were previously (Parse, 1981). In some cases, they lost control, as expressed by others with an AMI (Baldacchino, 2011). This may be a scary loss, showing that the individual does not know how to manage the situation. However, it appeared that the occurrence of an AMI had both positive and negative experiences, as confirmed by others (Baldacchino, 2011), and according to Human Becoming, there are new situations or events that provide new possibilities for those involved (Parse, 1987). Similarly, participants indicated that their AMI had become valuable because they saw their life from a new perspective, which resulted in prioritising friends and joy in life. One example is to not 'pretend' having suffered from an AMI and to be in the present time.

### **Lifestyle choices**

According to Human Becoming, every person is responsible for his or her choices (Parse, 1987). For example, a person's lifestyle reflects his or her choices, i.e., it is voluntary (Cockerham, 2005). The newly afflicted participants decided to see the AMI as a possibility to start a new life, as interpreted from the second principle of having power (Parse, 1981). Those who had a positive attitude to change habits had a healthier life-style. Others invoked their freedom by not making changes; instead, they wanted to live as they had lived before the AMI. Some refrained from exercise with the fear of having a second AMI. One study showed that people with an AMI, angina pectoris or hypertension had a higher level of kinesiophobia than those with other diseases (Bäck et al., 2013). It is difficult to understand what is behind choices to refrain from giving up bad lifestyle habits, but it may be due to a lack of information and support from health care facilities. According to the first principle (Parse, 1981), it is also an example of how an event can influence the everyday life of an individual (for example, new insights cause a person to consider his or her own needs).

### **Health Care**

Information during recovery was regarded as impersonal and scarce, and a lack of confidence influenced life in a negative direction, for example, socially. Lack of psychosocial as well as personal information about their diseases has also been confirmed in adults with congenital heart diseases (Pagé et al., 2012). It is remarkable that participants who are afflicted with a chronic disease do not feel sufficiently informed. According to Human Becoming, it is unacceptable to give everyone the same information and bears witness to non-individualised care

(Parse, 1992, 1999). The identification of patients who were willing to change their life-style habits but had not received help from health care is consistent with others who expressed a desire for more education on how to live healthy more than 12 months after their AMI (Bergman & Berterö, 2003). All of them with a disease who revealed such preferences would have received nursing grounded in Human Becoming out of the individuals' experience and description of a situation (Parse, 1999). Dissatisfaction with access to CCU was expressed by the newly afflicted participants, and the meaning of such contact was experienced by others with an AMI as satisfaction with the opportunity to contact relevant personnel at the hospital (not in primary care), as expressed 6 weeks after discharge (Condon & McCarthy, 2006).

What is most important out of the individuals' perspective would result in an individual plan focusing on *health and meaning* for each person in relation to a situation (Parse, 1999) and to see each person with a need for care who is sufficiently competent to influence his or her individual nursing plan (Parse, 2008a). It is not often mentioned in the Swedish guidelines how psychological consequences after an AMI affect an individual in their everyday life. An increased risk of a second AMI due to psychological consequences is only mentioned with reference to unclear evidence. The following sentence is mentioned about the worry for having an AMI: 'When a patient is experienced worry of suspected heart disease, would this one be offer contact with health care' (Socialstyrelsen, 2011). It is necessary that education be directed toward health care staff, explaining that the care of an individual does not end with discharge from the hospital. Care plans should rather be drawn up in cooperation with the individual and staff in both institutional- and primary health care. A systematic review including 16 studies aimed to investigate quality of life in patients with coronary heart diseases during rehabilitation. The findings showed that physical and psychological well-being were 'at least as effective' after home-based interventions compared to centre based interventions. Furthermore, social well-being was improved after home-based intervention due to individuality (Shepherd & While, 2012).

### **Time, consequences and acceptance**

One year after their AMI, more of the participants without mentors had a pessimistic attitude toward their recovery. Furthermore, there was a significant difference (according to between-groups ANOVA) in their appraisal of the length of time the illness was influential, i.e., in Timeline acute/chronic. Such differences would have been influenced by a lack of contact with someone who could serve as a role model. However, it was difficult to determine whether this insight was positive or negative because, in addition, this dimension showed a significant effect over time, with an increase in the mean values for participants. This implied

that new insights were obtained with the diagnosis of AMI as a chronic disease. Human Becoming explains that new experiences affect how individuals are becoming after an event (Parse, 1992), and range of consequences following the AMI showed significant effects between groups, with more negative score obtained for those without mentors. An intervention study including the same category of participants showed the same significant differences between the intervention- and control group 3 months after discharge (Petrie, et al., 2002). However, physical symptoms had decreased over the year for all participants. In line with Human Becoming (which asserts that health is a total experience [Parse, 1981]), the summarised results provide a varied and complex view of the participants' experience of health. For example, those with a fear of having a second AMI did not feel secure after their discharge from the hospital, and anxiety, in some cases, implied a return to the hospital. Another study measuring self-reported recurrent cardiac event by patients revealed an increased number of events, for example, re-infarction, by those with anxiety and/or depressive symptoms (Grewal et al., 2011). However, time mostly had an impact (positive) on well-being, and higher mental health scores were obtained one year after the AMI compared with the first measurement.

### **Meaning of environment**

The experience of health and meaning in everyday life stems from the environment (Parse, 1981), consistent with newly afflicted individuals who noted the importance of their environment. Living in the countryside was expressed as 'the quality of life', which is the goal of the practice methodology in Human Becoming (Parse, 1992). The description of being human indicates being part of nature, and nature will, in some cases, be decisive in reducing negative outcomes due to illness (Kaplan, 1992). In later descriptions of Human Becoming, the concept 'quality of life' was changed to *living quality* because it is not a static phenomenon (Parse, 2013). In line with this conclusion, living countryside could also be a limitation because it might be an impediment to personal meetings for some mentors and mentees (interpreted from the second principle [Parse, 1981]). The importance of the environment was sometimes related to opportunities to be in nature (read, the forest), irrespective of the physical condition. In view of Human Becoming, this could be an example of 'co-participation' and/or changes in relation to the environment, as mentioned in the assumptions and principles (Parse, 1981). I would like to return to the second assumption in Human Becoming with the reminder that being a human means to interact with the environment (Parse, 1987). It is understandable that participants note the environment and to be in nature as necessary for their health and well-being. Being a human, also implies being a part of the ecological system and, accordingly, to be a part of the environment. As much as we need nature, nature also needs us. The natural interaction between different parts have been known for a long time, which Platt et al. (1964) have described as



follow: *"Each organism within the woodland has its own unique and specific environment with which it interacts"* (p 26) and *"An environment is a dynamic complex, with constant interaction among the factors as cyclic and noncyclic changes in the environment"* (p 27).

### **Need for each other**

Freedom to choose is grounded in ontology to see individuals in a holistic view, with the meaning that existence is a process of receiving and giving between an individual and surrounding people as well as the environment (Parse, 1987). A matter of course about having a holistic view to understand illness experiences has also been expressed by Morse and Johnson (1991). Such processes explain how the newly afflicted appreciated the relatives who had been there for them and contributed to their security. Also in line with Human Becoming are the responsibility of people for their choices (Parse, 1987), which are sometimes a wake-up call. For example, when peer mentors were too pushy, they sometimes regretted their actions because it destroyed their relationship with their mentee. However, most of the peer mentors provided valuable support, and in some cases, this resulted in a new friendship and, hence, a win/win situation. This result is consistent with persons who appreciated participating in others' experiences of having an AMI (Bergman & Berterö, 2003; Arndt et al., 2009) and those who were repeatedly interviewed for the first five years after their AMI. The experience was positive for those who saw their illness as a turning-point and gave priority to taking care of relationships that were meaningful to them (Baldacchino, 2011).

In a study including people with psychological illness, peer support was described as a system of reciprocity and a unique understanding of, for example, emotional needs (Mead et al., 2001). The peer mentors in this thesis did receive additional and more positive insight about their own AMI after acting as a peer mentor. Their disclosure of lacking this type of support after their AMI has also been described by other peers (Ivarsson et al., 2011). The importance of relationship with others with the same illness was interpreted from the third principle and from the central concepts 'cause and effect' (Parse, 1981, 1992). It may be related to the expression indicating the need for meetings with others that was lacking in those who had not had this opportunity. The third principle explain that 'to power is natural' (Parse, 1981), which was confirmed by the mentors who grew as a person in response to their involvement in the study; they showed an increase in illness coherence and emotional representation (significant results according to a paired-sample *t*-test), which was interpreted as a positive result. One study evaluated people with ischemic heart disease who had been hospitalised or received open care and participated in mentor-led groups. The group sessions was led by lay mentors who were trained by CCNs and other professionals. There was also a control group. The

results showed significant differences between the groups in, for example, exercise levels and dietary habits, with improved ascribed to the intervention group (Coull, Taylor, Elton, Murdoch & Hargreaves, 2004).

According to Human Becoming mentoring model, a relationship means that unexpected circumstances may occur, and therefore, it is not possible to predict how a mentorship will develop (Parse, 2008b). The peer mentors noted that personal chemistry and similar life situations are requirements for a successful relationship, which is also a goal of the Human Becoming mentoring model (Parse, 2008b). However, the peer mentors indicated that they had experienced increased health over the year, which they ascribed to their commitment, and the mentees valued that their peer mentors shared their experiences with them. Human Becoming indicates that mentorship must be voluntary with ownership of the responsibility. The description 'moment to moment' is described in light of the 'ever-changing pattern' (Parse 2008b), which is one of the fundamental tenets of Human Becoming (Parse, 1981). It was not clear whether relatives or peer mentors were most supportive; however, eight of them who were offered a mentor, lived alone and this one may have provided a more essential, supportive role for them. A synthesis of the findings with the aim to investigate the meaning of the interventions with peer mentors in chronically ill persons, established that peer support seem to have a positive role in such groups (Embuldeniya et al., 2013).

## **Health**

Feelings of illness may sometimes occur without a diagnosis (Tengland, 2005), and according to Human Becoming, a man's health is not linear. This means that it cannot be explained in terms of, for example, 'more or less', which is a way to dichotomise health (Parse, 1981). The way to consider health is confirmed in the definition of the health declaration (WHO, 2005). However, measures of how newly afflicted individuals valued their health at the present time compared to one year prior resulted in significant variances over time with decreased mean values. This result may be interpreted as a worse feeling of the participants closer to their AMI and would be explained as feeling well one year before the AMI and the occurrence a half year before the assessment of something that negatively influenced health. Finally, one year after their AMI, whether they valued their health as much as they had one year earlier was obvious because their AMI had occurred at that time-point. This was also explained in the measurement of PCS (physical health) because newly afflicted individuals experienced a rapid increase in the mean value from baseline to the measurement performed one year after their AMI.

## Methodological considerations

It could be considered controversial to present symptoms and measurements of MCS and PCS - which would be seen as a way to 'dichotomise' health - when Human Becoming constituted the theoretical framework. However, my opinion is that the results reflect physical perceptions that influence psychological perceptions and vice versa. This is to have a comprehensive view of becoming a human who is afflicted by an AMI. The choice to use *everyday life* instead of *daily life* as an all-pervading concept resulted from perceptions and experiences described by the participants, not only in daily phenomena but also in their whole existence – both inside and outside. In that aspect, 'daily life' seemed to be too static, while 'everyday life' perceived as continuously.

## Theoretical framework

Inspiration was derived from phenomenology (partly through Human Becoming) to summarise and understand the phenomenon of peer support. According to Munhall (2012), qualitative research is humanistic and is naturally influenced by phenomenology because one fundamental part is to understand the individual experiences (p 25). Phenomenology in nursing research is 'used' in a way other than that used by philosophers because nurses derive meaning from experiences via participation. However, when an intervention is accomplished, the best perspective is that of the patient (Munhall, 2012 p 118-119). That is consistent with this thesis because the participants' perceptions and experiences were investigated. To understand the importance of peer support deeply, an intervention was considered as suitable, because according to Lauterbach and Frank (2012, p 180), to understand means more than just knowing, which in research means to take part in peoples' experiences. Examples have been presented in different situations in which the participants were involved in situations or events that cause about crises (idem). An explanation of the concept 'evidence' in nursing is how reality and 'the moment now' is working (Parse, 2008a). The 'many-sidedness' of Human Becoming allow this theory to be used in different contexts. For example, in a study attempting to understand the acceptance of death in people in palliative care, Human Becoming was used as a framework to understand and interpret the phenomenon (McLeod-Sordjan, 2013).

Experiences of moving forward were studied and conceptualised by Human Becoming, and the data were collected in line with the theory by dialogical engagement, i.e., a special way to *be with* someone (Chen, 2009). The authors (in line with me) thought that the language was complicated. This was also mentioned in a review of Parse's books; the version from 1981 is difficult to understand for

people who are not familiar with the philosophy (Morrow, 2012). It is clear, in a unique way, that the philosophical fundamental tenet is in Human Becoming (Sarter, 1997). A study of the Human Becoming research method investigated the phenomenon 'meaning of feeling grateful', which was considered as a parallel to health and quality of life and reflected the patient's own choices (Hart, 2013). Interesting studies have used data collection in the form of a *dialogue* and presented results obtained by both the participant and the researcher. Although Human Becoming has not been used fully in this thesis, a synthesis out the theory was helpful to understand the phenomenon, perceptions and experiences of having had an AMI and the importance of peer support.

## **Design**

According to Parse, Human Becoming in research would be confirmed as descriptive in an inductive process (Parse, 1981). Human Becoming did not influence how the studies were accomplished in the thesis because having an inductive approach means to take up a neutral attitude without expecting something special about the investigated phenomenon (Patton, 2002). However, over time when the entire results increase, Human Becoming appears as a suitable theoretical framework.

Explanation of the design: a prospective design explains the interest to investigate the effects of the intervention in the context of the thesis in a longitudinal manner (Polit & Beck, 2012, p 225). A longitudinal design indicates that data are collected at more than one time-point over a long time (Polit & Beck, 2012, p 186), for example, to investigate changes over time. It was not possible to accomplish a 'randomised controlled trial' (RCT) under the circumstances that occurred; rather, the design was quasi-experimental. Thus, the studies (I, II, III) included two groups of participants from whom data were collected before and after an intervention, and the comparative part, consequently, showed that the included groups were not randomised participants (Polit & Beck, 2012, p 217).

We used different methods because they were complementary. A study in which mixed method studies were analysed, showed that integration could occur in different phases; for example, depending on the results of the analyses or during presentation of the results (Creswell, Fetters & Ivankova, 2004). Lund et al. (2012) elaborated on the positive aspects of a mixed method in a summary of four steps, which showed the following (shortly): easier to receive research answers out of combined questions; a way to show different sides of a phenomena using a combination of methods; complementation of different findings is possible to show nuances of more than one study; contradiction of different methods provides the possibility of increased insight about the research area (idem). In an ongoing

project, Sandelowski et al. (2012) is attempting a method to investigate how findings from studies with different designs are preserved after their synthesis. For example, results that are not significant in a quantitative study may be considered significant after their incorporation with results from other studies and expressed in a pooled result. In this thesis, a mixture of methods was planned initially, and questionnaires were carefully chosen. The choice to mix findings from the studies to generate the result occurred during the research process. The goal was to compile the results cautiously without excluding valuable portions.

### **Intervention**

The intervention was designed to take a chance. Unfortunately, our initial idea to offer a meeting between peer mentors prior to their commitment was impossible owing to the context of the thesis (sparsely populated areas). This procedure could have been helpful for uncertain mentors to feel more comfortable. They received repeated information and conversations by phone, but that was not sufficient for some of them who wished for some sort of education. According to the Human Becoming mentoring model, mentor and mentee should have common interests (Parse, 2008b). This was also expressed by some of the mentors, but unfortunately, it was not possible to incorporate but can be learned from.

### **Sample**

There was no control for the newly afflicted participants or for external, influencing factors. The participants were widespread in the three counties and over time, and matching was not possible under such circumstances. The choice to separate them into those who were offered peer mentors and those who were not depended on interests to receive a clear view of the importance of the intervention and peer mentors, and not to quantify significant differences. They were named *with or without mentor* due to the determination to use the same designations during all of the studies. Therefore, the name comparison group was dropped, even if it was usable in connection with the design described in the Methods section (Polit & Beck, 2012, p 217). It was not possible to perform a RCT due to the duration of doctoral studies. It is also difficult to determine whether a RCT would provide other results, but it would have provided possibility to control and compare participants to draw conclusions. There is no reason to speculate whether a RCT would have provided better results because I received results that were reliable and trustworthy answers to the main aim. The number of newly afflicted that CNNs requested permission to send their contact information but abstained, is unknown, which could be considered a limitation.

The interviews included the same 20 participants with peer mentors (n=11) and without mentors (n=9) (I, III). Suitable numbers of participants in an interview study are considered to be 15 +/- 10 (Kvale & Brinkman, 2009 p 130). The participants who first reached one year after their AMI were asked to participate until a sufficient number of interviews had been accomplished. The number of respondents was not determined before the data collection started; instead, the content was used to determine when the information was sufficient based on the main aim of the thesis (Kvale & Brinkman, 2009, p 129). Four of the participants without mentors did not participate in the study and provided no explanation.

The sample in study II consisted of newly afflicted participants who had answered the questionnaires on three occasions; with mentors (n=28) and without mentors (n=33). Power analysis showed that when two groups answered at three time-points, it was suitable to analyse the results using two-way ANOVA for a mixed design, i.e., a two-sided test with a significance level of  $p \leq 0.05$ . The effect size ( $=0.80$ ) implied a minimum of 25 individuals per group were needed, and therefore, relevance was achieved in this study. To investigate changes over time, repeated measures is important in comparative studies. Repeated measures can reduce the sample size several percentage points depending on the number of measurements (Vickers, 2003).

Study IV included peer mentors, and the mixed design of the study explains why the number of participants differed in the two portions. In the quantitative portion, an analysis using a paired-sample *t*-test was conducted to investigate whether changes occurred over time. Therefore, only questionnaires answered at both occasions were involved (n=22). This is a very low number; however, it is consistent with other mixed studies as one study often complements the other one. The interviews were reported by those who conducted them (n=15), and because content in interviews was consistent with the main aim of the thesis, this strategy seemed to be sufficient. Notably, all of those who reported interest in participating in the interviews answered the questionnaires on both occasions.

### **Data collection**

Although this thesis is based partly on quantitative studies, quality of life was measured repeatedly, which would be seen as acceptable in view of Human Becoming. The mixed design provided an opportunity for parallel processes during the data collection, which was stimulating. Interviews (I, III) with the same newly afflicted participants were aimed to provide insight regarding their perceptions and experiences during the first year after an AMI. According to Human Becoming, the interviews are presented as a dialogue in which the

researcher is *being with* the participant and discussing life experiences (Parse, 1987). I have accomplished 'interviews'; however, they were performed in a mutual way. Interviews were accomplished in the same way, using the same areas of questioning irrespective of the participant.

The interviews durations differed owing to differences in personalities rather than unwillingness; short interviews often contained as much information as longer ones. Initially, one interview study was planned, but extensive material resulted in the decision to divide it into two studies. The effects of other factors were not controlled because the intention was to turn to lay people in their natural environment without engaging professionals. It was not possible to determine which relationship, and in to what degree, this feature affected perceptions after AMI for participants with a mentor.

The HRQoL group in the care research section at Sahlgrenska University Hospital in Gothenburg, Sweden, granted permission to use questionnaire SF-36, and registration for this project was obtained. However, when it was time to analyse the questionnaire, rights to the issue license had been taken over by a company in the USA, which caused temporary problems. However, licenses were received for the use of SF-36 (II, IV). In study II, there was no control to investigate whether the differences between those with and without a mentor occurred from the beginning of the interaction. Even if the power analysis seemed sufficient to validate the results, unfortunately, the questionnaires could not be used from all participants. However, to compare changes between groups over time, it was necessary to only include those participants who provided answers on all three occasions. Those who dropped out internally are not presented for II or IV because all of the questionnaires had been filled in completely. However, if this was a 'Hawthorne' effect, it was not possible to know: a Hawthorne effect occurs if an outcome (dependent variables) results from what participants believe is expected (Polit & Beck, 2013).

A mixed design was used (IV) to obtain a broader insight regarding the perspective of the peer mentors and how they had experienced their commitment. It may seem controversial to incorporate them, but without their involvement, the whole study would be lost. The intervention, i.e., peer mentoring as it was performed herein, was unique, and therefore, there was no hesitation to include them in the thesis. This inclusion provides a unique perspective of the phenomenon of peer support. Only two dimensions were analysed in each questionnaire designed to investigate any tendencies to change in addition to the results of the interviews. The interviews were accomplished by phone, and the

contents were interpreted as sufficient for the purpose. According to Kvale and Brinkman (2009, p 165), phone interviews in qualitative research provides several advantages. For example, there is the possibility of generating results despite long distances. In one study, approximately half of the interviews were accomplished using semi-structured questions by telephone or face-to-face. The depth and themes of the methods were compared and did not show any differences (Sturges & Hanrahan, 2004), and my impression was that the mentors felt comfortable with the interview situation. The decision to perform the interviews resulted from the realization that the questionnaires do not require a real understanding of what it means to be a peer mentor. Therefore, they were performed later than the other analyses.

It may seem controversial to use quantitative data when Parse indicated that this type of study reduces phenomena to observe only parts of the whole, while human science provides the *meaning* of phenomena. However, I will assert that the questionnaires aimed to provide a comprehensive picture of the summarised dimensions. Parse intended that research focus on quality of life, especially from questionnaires without the possibility of individual descriptions of the phenomenon in own words (Parse 2013). My opinion is that the mixture of methods and participants from the studies in the thesis is sufficient to obtain an accurate result.

## **Analysis**

The results of the studies were analysed together to obtain a compiled result with the goal of achieving a totality. Because in my mind it was difficult to separate the outcome, all four studies complemented one another. A methodological consideration of analysis is presented below.

The choice of mixed design was easy, because it allowed me, as a doctoral student to use different methods. Analysis of the questionnaires provided a deductive approach because the analysis resulted from issues evaluated, while an inductive approach (used for the interviews) means that the data formed the results without preconceived meanings. The concepts describing the validity and reliability of quantitative research are not applicable to qualitative research. Instead, *trustworthiness* is a more suitable description, with an explanation of the concepts of credibility, transferability, dependability and confirmability (Graneheim & Lundman, 2004; Shenton, 2004). Trustworthiness was fundamental in how the interview material was treated. The interviews were analysed by qualitative content analysis, which was judged as the correct way to generate the results. According to Krippendorff (2013), this method permits, in a systematic way, the



investigation of interview content. Content analysis is useable from different contexts and is explained as *“a research technique for making replicable and valid inferences from texts (or other meaningful matter) to contexts of their use”*(p24), providing insight and understanding of the phenomena being investigated (idem.) The analysis is performed carefully with respect to the content, and the results are compiled based on the content of the interviews and not on preconceived categories of the authors, achieving dependability (Long & Johnson, 2000). The most important part of reliability is replicability (Krippendorff, 2013).

To validate the SF-36 in clinical contexts, two longitudinal studies have been conducted in women and elderly people. The participants (N=1 295) were divided into seven age strata, six including only women and one consisting of 218 men. The other study consisted of participants with different physical and/or health statuses based on a medical diagnosis or no diagnosis. The analysis included the main parts of the SF-36, and the relative validity of the eight scales was measured. The cross-cultural stability of the SF-36 was confirmed (Persson et al., 1998). A study performed to validate the IPQ-R consisted of people with eight different diagnosis categories (Moss-Morris et al., 2002). This questionnaire has been used in research in Sweden, e.g., to research perceptions of illness after an AMI. The mentioned study was longitudinal and included 236 individuals; measurements were performed 1 week and 4 months post-AMI (Alsén et al., 2010a). Reliability in the measured portions in IPQ-R and SF-36 were interpreted as sufficient because the values according Chronbach's alpha coefficient, mostly measured  $\geq 0.7$ .

One study (IPQ-R) showed that responses differ between the perception of acute and chronic illness. This result triggered an interest in investigating the perception of illness, which can be decisive in the outlook of a patient as well as his or her willingness to follow the treatment advice. The perception of illness is also significant for the management capacity of an individual (Leventhal, Diefenbach & Leventhal, 1992). Two dimensions of interests in IPQ-R and two health indexes in SF-36 (IV) seemed to be suitable for the aim of the study. The number of participants was not sufficient to perform a study, and furthermore, the mentors were not studied with respect to their illness in the same way as the newly afflicted individuals. However, AMI is considered a chronic disease, and therefore, it is interesting to investigate whether mentorship has an effect on their own experiences of an AMI. The choices of the dimensions to study seemed obvious.

Only 65% (n=22) of the mentors (IV) answered the questionnaires on two occasions. The percentage was acceptable, but the number of answerers was too small. All of the included questionnaires were filled in completely. No power

analysis was performed because the number of measurements was too few to draw conclusions. This was another reason to only use a few dimensions and to use these dimensions as a complement to the interviews.

### **Ethical considerations**

It is debatable whether it is ethical to offer contact to peer mentors to only a portion of the newly afflicted participants. However, the participants without mentors had knowledge that the other participants had received such contact, and some of them expressed that they lacked this type of contact. All of contacts were characterised by openness, and ethical rules were followed out of principle and common sense, with respect for all of the participants in sensitive situations and the roles they had participated in.

### **Conclusion**

Having a life-threatening illness such as AMI results in a return within a short period to a life with to the demand for a change in habits, body and mind in the form of attitudes; it is similar to asking the afflicted individual to turn over a very large stone. Some begin to lift and investigate what is hiding under the stone but immediately replace it. Others lift the stone and try to turn it over, looking for someone to help; however, they give up and put it back again. Some individuals do the same without giving up, and sometimes they succeed themselves or manage it with support and help from others. This metaphor would partly reflect the results of the thesis. Participants with a mentor demonstrated a relationship that worked well, and some appreciated that someone really cared for them. It was a relief to know that the mentor had gone through the same event, sometimes more seriously, which contributed to the security of the participant. Although the mentors not had received an education regarding being a mentor, most of them acted well as mentors. I have expressed this finding in the thesis as a win/win-situation for most of the participants. The mentors grew with the task because they felt that their experience was valuable, and this contributed to feelings of pride and of being unique. Their experience also confirmed that recovery after an AMI is a process that occurs over time, i.e., becoming one with the illness.

Newly afflicted participants experienced psychological consequences in the form of fear and anxiety during recovery, which was a negative surprise for them. Some blamed their ignorance on health care. This can be interpreted as an example that medical and nursing care have not developed sufficiently in consideration of psychological needs, after an AMI. However, after one year, most of the newly afflicted participants had returned to a life they appreciated, sometimes with new priorities. Families and relatives were meaningful, as were peer mentors for those

that received them, they were even thankful and had learned the cause behind their symptoms. Furthermore, new insights were obtained that enriched their lives compared with before the AMI. Clearly, each person perceives and experiences his or her illness in a unique manner, for example, although some handled it well, it was a challenge to change habits associated with everyday life. It is difficult to understand what underlies choices to abstain, but in some cases, it was explained by a lack of support from health care, in opposition to the guideline recommendations. One routine that was followed by participants was to go for a walk every day. However, as confirmed within this thesis, other authors consider information regarding psychological and social consequences that may occur after an AMI to be too impersonal and, in some cases, incomplete. It also has been expressed that some patients did not receive help and support to change their lifestyle despite having asked for this to be provided.

### **Clinical implications**

Over the last decades, the rapid development of medical care has been observed within many specialised fields in the form of knowledge, treatments and medicine. Clearly, to recover after an AMI takes time because values other than satisfaction about blood pressure, lipoproteins and weight reduction must be achieved. One common interest of health care professionals is people with an illness, and common is a wish to decrease negative consequences as much as possible. This places demands on how nursing is performed, which in turn depends on how the organisation is constructed. A continuous dialogue is needed between nurses in CCUs and nurses in open health care. There is something lacking at an organisational level between hospitals and open care facilities, potentially to a higher degree in sparsely and/or rural counties.

There are many valuable results of theses and studies in nursing care that are ignored in clinical work. It is increasingly necessary to use such research in parallel with medical research. It is well known that lay people with the same experiences have a unique ability that is difficult for health care to achieve. This ability is described in many studies of different illnesses, and it should be utilised in health care more often. It is clear that support is best in illnesses that must be managed and changes must be incorporated, i.e., in the environment where every day is lived. It would be beneficial for CCNs to communicate with discharge to encourage newly afflicted individuals to contact others with an AMI.

### **Further research**

Health care and the possibility of curing diseases have developed rapidly over the last decades, resulting in increasing costs to society. Therefore, it becomes

necessary to use knowledge that is accessible and to develop parts that are cheap but that matter for individuals. Studies are needed, to compare outcomes in densely and sparsely populated areas and to investigate whether there are differences in perceptions and experiences, as well as access to rehabilitation programmes and other types of support. The results of such studies will indicate areas requiring increased efforts. It will be interesting to develop an interactive support, perhaps by supplying tablet computers to people without computers and/or knowledge in such areas.

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