

# Living with unexplained chest pain

Experiences of information needs and physical activities

by

Ingrid Ølfarnes Røysland

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Faculty of Health Sciences  
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University of Stavanger  
N-4036 Stavanger  
NORWAY  
[www.uis.no](http://www.uis.no)

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## Preface

My intention and feeling while writing this thesis can best be summarized with the words of T. S. Elliot (1915):

Let us go then you and I

...

To lead you to an overwhelming question ...

Oh, do not ask, "What is it?"

Let us go and make our visit.

With the intention to make the voices from the patients be heard

The journey of writing this thesis has been like travelling a long and winding road. For different reasons outside of my control, it was not possible for me to carry out my study as originally planned. During my work with this thesis I was physically active, as recommended. However, herein lies the balance of vulnerability and capability, as the results have highlighted. In December 2015 I was seriously injured while riding my bike. The road back to recovery has been a long one, but it has given me new insights from another perspective. I have learned the importance of describing human experience and understanding first hand from an outside and inside perspective. However, the perceived world endures only through the reflections, shadows, levels and horizons between things, which are marked out by themselves (Maurice Merleau-Ponty 2012).

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Stavanger, September 2019

Ingrid Ølfarnes Røysland

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## Abstract

**Background:** Unexplained chest pain is a common condition in medical settings. A large number of these patients will continue to suffer from chest pain after medical examination with negative findings. Unexplained chest pain covers many possible complaints, as there are a number of possible factors that can contribute to the condition. To meet patients' expectations, health professionals need to know more about experiences in relation to the information needs of patients with unexplained chest pain. Physical activity is recommended. At the same time, physical activity is one of the major avoidance behaviours in patients with coronary heart disease. There is a need for understanding of experiences of living with unexplained chest pain.

**Aim:** The overall aim of this thesis was to explore and describe experiences related to living with unexplained chest pain. This has been carried out in three steps. The specific aim in step I was to explore the information needs of patients with unexplained chest pain, and how these needs were met by health professionals during medical consultations in a cardiological outpatient clinic. On the basis of the interviews in step I, the specific aim in step II therefore was to achieve increased understanding of the meaning of physical activity in daily life for people with unexplained chest pain. Step III was an extension, explaining the transitional process people with unexplained chest pain undergo while participating in exercise training over time.

**Method:** A descriptive and explorative design was used. Three studies with different qualitative methodological approaches were performed, which remained separate during the analysis phase. Study I has an inductive design, and content analysis was performed in regard to the information needs of patients with unexplained chest pain (Graneheim & Lundman, 2004). Study II has an inductive design with a phenomenological hermeneutic approach (Lindseth & Norberg, 2004).

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Study III has an inductive design to collect and analyze qualitative data that aims to develop theories grounded in real-world observations (Strauss & Glaser, 1967; Glaser, 1978).

**Results:** Study I described the uncertainty as exploring the information needs of patients with unexplained chest pain. Uncertainty emerged from unanswered questions, as well as experiencing lack of focus on individual problems. Additional aspects of uncertainty related to physical activity were also revealed. In Study II, an existential uncertainty related to the chest pain and physical activity was identified. The results were interpreted as a balancing act between existential uncertainty and certainty. In Study III, patients participated in a high intensity exercise programme. A transitional process was revealed, whereby vulnerability was confronted under safe and supportive conditions. Through this process, patients had to balance their existential uncertainty.

**Conclusion:** A special focus must be complemented with the inclusion of a person-centered approach to meet patients' beliefs, perceptions and expressions of feelings related to experiencing unexplained chest pain. For health professionals, there are revealed challenges in understanding the vulnerability in people balancing between existential uncertainty and certainty in connection with doing or avoiding physical activity while living with unexplained chest pain. The transition while participating in a high intensity exercise training programme was described as a process of becoming more capable. This training can be understood as experiences that change the understanding of what the person in question can and dares to do.

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## Presentation of articles

- I. Røysland, I. Ø., Dysvik, E., Furnes, B., & Friberg, F. (2013). Exploring the information needs of patients with unexplained chest pain. *Patient Preference and Adherence*, 7, 915-923.
- II. Røysland, I. Ø., & Friberg, F. (2015). Unexplained chest pain and physical activity: Balancing between existential uncertainty and certainty. *Qualitative Health Research*, 26(2), 215-126.
- III. Røysland, I. Ø., Friberg, F., Brinchmann, B. S., Svello, S. N., Valborgland, T., & Larsen, A. I. (2016). Confronting one's vulnerability – people with unexplained chest pain participating in a high intensity exercise-training programme. *Journal of Clinical Nursing*, 26, 2006-1015.

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*To my father Arnfinn, who convinced me of the  
power and vitality of "homo capax"*

## **1 Introduction**

Unexplained chest pain is sometimes called the “puzzling condition”. Practically since the advent of coronary arteriography, the condition known as “non-specific chest pain”, “chest pain with normal coronary arteries”, “atypical chest pain”, “cardiac syndrome x” “microvascular dysfunction”, and “microvascular angina” has puzzled health professionals and patients (Kaski, Eslick & Merz, 2013). A patient shares her experiences of living with unexplained chest pain as follows:

It’s my arm that’s been painful – it’s hindering me. It’s frustrating to get different verdicts (on investigation). I’m getting a little anxious. My arm quickly becomes sore when I start walking. It starts in the arm and then I get pressure in my chest. Had capsulitis before. I can get that when I exercise and when I heave myself up a bit. First pain in my arm but it varies – it can come after 1 minute or after 5 minutes. I have to hold my arm – it’s so painful – and then I feel the pressure in my chest. I’m participating in this project because I’m curious. I didn’t have anything (heart condition), but at the same time I did. It’s very frustrating!

This patient expresses concern and wonders about her chest pain. It is also a narrative about the possible challenges to health professionals in understanding what the patient is expressing in terms of signs and symptoms. The expression “unexplained chest pain” has often been used when referring to chest pain without obvious organic cause (Ockene, Shay, Alpert, Weiner & Dalen, 1980; Robertson, 2006; Garroni & Fragasso, 2018). Unexplained chest pain constitutes both a diagnostic and therapeutic challenge, and in addition to the illness experience, it challenges daily life for the patient. Busvold and Bondevik (2018) point to the fact that chronic pain constitutes a considerable element of medically unexplained physical symptoms.

In recent decades there has been an increase in research related to biological explanations for unexplained chest pain, specifically progress in the diagnosis of myocardial ischemia (Kaski, Crea, Gersh & Camici, 2018). Of special interest is the change in paradigm from addressing unexplained chest pain as purely macrovascular to microvascular disease (Kaski et al., 2018). Notably, this thesis has been conducted during a period of intense biological/medical research. Even if the focus of the thesis is living with unexplained chest pain, it is important to be aware of the change in explanatory focus. At the beginning of my thesis, unexplained chest pain was mainly seen as caused by factors outside the heart. As my thesis progressed, the biological explanations of chest pain have become more and more obvious. According to Safdar et al. (2018a), the coronary microcirculation represents one of the contemporary frontiers in cardiology research, and it is suggested that more light must be shed on the growing field of “coronary microvascular dysfunction”.

Regardless of the level of biological explanation, living with unexplained chest pain impairs daily life and life circumstances (Chambers, Marks & Hunter, 2015). These persons have symptoms of chest pain, but there are often no signs, as microvascular function is hard to visualize directly (Safdar, Ong & Camici, 2018b). According to Jonsbu, et al., (2009), for the majority of people referred to cardiac outpatient clinics in Norway for examination of chest pain, no signs of a cardiac condition were found. The vast medical-technical advances of the last century have created increased possibilities for investigation and treatment. However, in this regard there is perhaps a risk of undermining a person’s experienced illness due to a tendency to seek objectively measurable disease. Health care practice needs to embrace both aspects.

According to Chambers et al., (2015) research into what they call “non-cardiac chest pain” has largely emphasized excluding coronary disease rather than facilitating clear and concrete management of the chest pain. Busvold and Bondevik (2018) point to the need for greater attention to

the patients' experiences to place their symptoms and understand bodily changes. It follows that patient narratives often lie buried under their life- and disease histories. In order to understand the individual on the body's premises, the person's sense-making activity must be explored. According to Busvold and Bondevik (2018), a greater awareness of the individual's experience includes the patient in a manner that eliminates an unnatural disconnect between the patient and the affliction.

One aspect mentioned in connection with patients' experiences of non-cardiac chest pain is a lack of understanding of their condition (Webster, Thompson & Norman, 2015). A recent doctoral thesis (Nolan, 2017) made enquiry into the help-seeking experience of people referred to a rapid access chest pain clinic (a cardiac physiologist-managed clinic). The findings revealed that some participants expressed frustrations about not getting answers about their symptoms, and some felt they were wasting the health professionals' time. According to Nolan (2017), there are challenges around symptom attribution, attitudes to help, and seeking a response to symptoms.

In line with the increased body of research investigating the cause of unexplained chest pain and various treatments (Chambers et al., 2015; Suhrs et al., 2018), physical activity has become an important part of rehabilitation programs for cardiac heart disease (Anderson et al., 2016; Dibben et al., 2018; Khanji et al., 2018; Kaminsky et al., 2019). Equally, there are indications of avoidance behaviour in relation to physical activity (Nelson & Churilla, 2015; Jonsbu, Dammen, Morken, Moum & Martinsen, 2011). People with unexplained chest pain may avoid physical activity due to concern about their hearts (Jerlock, Gaston-Johansson & Danielson, 2005; Simonÿ, Pedersen, Dreyer & Birkelund, 2015).

Chest pain is one of the most common medical problems in medical settings worldwide (Laederach-Hofmann & Messerli-Buergy, 2007; Niska, Bhuiya & Xu, 2010; Bhuiya, Pitts & McCaig, 2010; Safdar et al.,

2018a). Cardiac heart disease also ranks as one of the most expensive healthcare conditions (Shaw, 2013; Nasir & Veledar, 2018). Ongoing symptoms, including chest pain with continuous medical consultations, constitute a large component of the care cost (Merz, Eslick & Kaski, 2013; Safdar, Ong & Camici, 2018b) and this increases due to the cost of new investigation methods, for example, fractional flow reserve (Farzaneh-Far, Schwitter & Kwong, 2019). Thus, healthcare costs related to cardiovascular disease have been escalating rapidly.

A perspective permeating this thesis advocates that we, as humans, are capable, relating and embodied subjects, but at the same time vulnerable and utterly limited by our biology. This is also highlighted by the French philosopher Maurice Merleau-Ponty (2012) when he discusses the human being as an intertwinement between body and mind/biology and existence. Merleau-Ponty (2012) uses the expression “the lived body” to put forward that the body is not only biological, but also experiential. This has to be taken into account when studying persons with pain, but without an identified cause or diagnosis. At the same time, persons with unexplained chest pain are subject to questioning the illness experience and cause of pain in relation to what has been recommended by health professionals. More in-depth understanding for adequate patient information is needed. Better understanding will contribute to better current and new forms of care. This is grounded in the notion that all human beings have their own unique experience related to (as in this thesis) different symptoms, illness experiences and life situations. This thesis contributes to filling the knowledge gap from the patients’ perspective. In the present thesis, both the terms “patient” and “person” are used. As a human being, you are always a person and sometimes a patient.

All in all, this calls for further exploration of information needs and experience of physical activity for persons with unexplained chest pain.

## **2 Aims**

The overall aim of this thesis was to explore and describe experiences related to living with unexplained chest pain. This has been carried out in three steps.

In Step I, the specific aim was to explore the information needs of patients with unexplained chest pain, and how these needs were met by health professionals during medical consultations in cardiological outpatient clinics, as experienced by the patients. The interviews conducted to achieve this highlighted unmet information needs in relation to physical activity. Based on these interviews, the aim of Step II therefore was to achieve increased understanding of the meaning of physical activity in daily life for people with unexplained chest pain. By extension, the aim of Step III was to describe the transitional process people with unexplained chest pain undergo while participating in an exercise programme over time. This knowledge might facilitate the identification of challenges for patients living with unexplained chest pain.

The thesis addresses the following three research questions:

1. What are the information needs of people with unexplained chest pain, and how do health professionals meet those needs during medical consultations, as experienced by the patients? (Paper I)
2. What are the experiences of physical activity in daily life for people with unexplained chest pain? (Paper II)
3. How can the transitional process that patients with unexplained chest pain undergo while participating in an exercise programme over time be described? (Paper III)

*Aims*

---

### **3 Background**

Although unexplained chest pain from the perspective of the patient is the focus of this thesis, it is important to take into account biomedical issues when trying to understand illness experiences. This has to be seen in the context of patients as persons have their own way of handling illness in daily life. This will be highlighted in different ways in the following parts of the thesis. Firstly, different perspectives on pain are introduced to understand circumstances under which patient experiences are generated. Influencing factors for unexplained chest pain are then presented, followed by the concept of physical activity, which also includes high-intensity exercise training. Finally, organization of health care is described.

#### **3.1 *Perspectives on pain***

A widely used definition of pain, recommended by the International Association for the Study of Pain, defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey et al., 1979). However, pain is complex and subjective (Melzack & Casey, 1968).

Melzack and Casey’s (1968) pain assessment model is widely recognized (Zaccagnino & Nedeljkovic, 2017). It consists of three dimensions: sensory-discriminative, affective-motivational and cognitive-evaluated. Some years later, Melzack (1999) extended this bio-psychological model of pain to the Neuromatrix theory. According to this theory, the perception of painful stimuli does not result from the brain’s passive registration of tissue trauma, but from its active generation of subjective experiences through a network of neurons (Seymour, 2019). This means, for example, that patients’ experiences from earlier in life can be part of the experienced pain.

However, according to George (2017), professionals often follow a narrower definition of “sensory experience associated with actual tissue damage”. Recent neuroscientific research (Jones & Brown, 2018) claims that pain perception and pain behaviour are reinforced through factors such as vulnerability. A Norwegian theoretical study (Busvold & Bondevik, 2018) about medically unexplained physical symptoms points out the need for closing the gap between biomedical perspectives and more humanistic approaches, and the importance of viewing the body from both a biological and existential perspective. Such an enhanced understanding of body, symptom, biology and existence may lead to more constructive clinical encounters with patients with unexplained chronic pain (Busvold & Bondevik, 2018).

According to George (2017), there is a need for a paradigm shift in the approach to pain management. Thus, George (2017) claims that current pain management mainly focuses on pain relief without considering suffering. This challenges health care providers to consider how pain is (understood) expressed in a biological psychological and existential sense. According to Busvold and Bondevik (2018), the patients’ unexplained pain has its reasons, purpose and meaning hidden in their mental and bodily history. Thus, an openness to unexplained pain is needed.

In summary, Melzack and Casey’s pain assessment model (1968) has further been categorized into additional domains such as pain intensity and quality, personality, psychosocial impact, physical/social functioning, patient beliefs, coping and quality of care (Zaccagnino & Nedeljovic, 2017). Returning to this thesis, the intertwinement between biology and existence expressed in patients’ illness narratives about chest pain has to be taken into account.

### **3.2 Influencing factors on unexplained chest pain**

Although chest pain is considered a characteristic symptom of coronary artery disease, a number of other factors can contribute to the condition of chest pain (Bass & Mayou, 2002; Laederach-Hofmann & Messerli-Buergy, 2007; Marinescu et al., 2015). Non-cardiac factors, such as pulmonary, musculoskeletal, gastrointestinal and psychiatric, are often mentioned in connection to differential diagnosis (Bass & Mayou, 2002; Mikhail et al., 2018). The results of a recent study (Foldes-Busque et al., 2017) indicate that panic attacks may explain a significant proportion of emergency department visits for non-cardiac chest pain. The two major hypotheses explaining the pathophysiological mechanisms of non-coronary artery disease are based on abnormal microvascular dysfunction and altered pain perception (Makarović, Makarović, Bilić-Ćurčić, Mihaljević & Mlinarević, 2018). Cardiac ischemic causes of chest pain can be coronary spasm, atherosclerosis and inflammation, endothelial dysfunction, sympathetic and smooth muscle dysfunction (Marinescu et al., 2015).

Despite angiographically normal coronary arteries angina is a debilitating condition that affects men and women, but mainly the latter (Lanza, De Vita & Kaski, 2018). Overall, 50-80% of women assessed for chest pain have angiographically normal coronary arteries, or non-obstructive cardiac artery disease.

A recent study (Safdar et al., 2018a) shows that despite low-risk profile, nearly one-half and mostly obese emergency department patients with chest pain (without signs of myocardial infarction or coronary artery disease) had coronary microvascular dysfunction. According to Safdar et al. (2018a) these results can explain the high rates of return visits associated with chest pain.

Research on unexplained chest pain can also be related to different psychological perspectives and concepts. There are high rates of comorbid emotional disorders, particularly anxiety disorders in

unexplained chest pain (Mourad, Jaarsma, Strömberg, Svensson & Johansson, 2018; Rushton & Carman, 2018; Tremblay et al., 2018; Pardue, White & Gervino, 2019). Taking into account that chest pain is associated with coronary artery disease, it is understandable that it is one of the most anxiety-provoking and uncertainty provoking medical complaints for patients (White & Rosenbaum, 2013). Persons with unexplained chest pain are not a unitary group. They respond to various levels of explanations and reassurance regarding the illness. There is also a difference in medication and use of psychological techniques (Chambers et al., 2015).

There has been growing understanding of pain as a complex perceptual experience influenced by a wide range of psychosocial factors, including the meaning of pain to the person's beliefs, attitudes and expectations (Turk & Okifuji, 2002). Stress is often described as one factor in the explanation of disease. An often used definition for stress is Selye's (1956): the non-specific response of the body to any demand made upon it. According to Selye (1976) the stress response in the body is the same kind for both positive and negative stressors. In line with Lazarus and Folkman (1984), stress is seen as a result between the person and the environment. When a person's resources are exceeded, stress develops. However, intra individual analyses indicate that people are more variable than consistent in their patterns of handling stress (Folkman & Lazarus, 1980). An example from research is a sample of hospitalized cardiac patients showing that uncertainty in illness has a significant impact on both anxiety and depression (Giammanco & Gitto, 2016). Uncertainty in illness has a significant impact on the possibility of augmenting levels of both anxiety and depression.

Returning to the focus of my thesis, factors like those described above may influence experiences and expressions of pain.

### *3.2.1 Coronary microvascular dysfunction*

Many bio-medical theories have been proposed to explain chest pain, including an impairment in coronary flow reserve (Chauhan, Mullins, Petch & Schofield, 1994), microvascular spasm (Kaski, 1998), undetectable abnormalities of small coronary arteries (Maseri, Crea, Kaski & Crake, 1991), oestrogen deficiency (Ross et al., 1996), patchy constriction of pre-arteriolar vessels (Maseri et al., 1991), and impaired endothelial function (Egashira et al., 1993). Explanations have also focused on neurophysiological differences in pain perception (Rosen, 2004). Research (De Vita et al., 2019) indicates that the mechanisms responsible for coronary microvascular dysfunction include both reduced coronary microvascular dilator function and enhanced coronary microvascular constriction. Moreover, the impaired microvascular dilator function may involve both endothelium-independent and endothelium-dependent mechanisms.

According to Safdar et al. (2018a), the clinical profile of individuals with coronary microvascular disease was surprisingly similar to those with normal flows. There was little correlation with traditional predictors of cardiac artery disease, which makes routine screening particularly challenging. There is a need to look beyond traditional predictors of cardiac artery disease to develop new screening measures for coronary microvascular disease, using a more holistic and sex-specific approach, partly related to the fact that there are more women with chest pain (Safdar et al, 2018b). According to Safdar (2018b), this underscores the challenge of identifying effective therapies for treating patients with microvascular disease. It also accentuates the need to focus on the experiences of living in the borderland between being diagnosed or not, and still being ill. Returning to my thesis, this means we need openness in understanding the patient's chest pain and the experience of living with this pain.

### **3.3 Physical activity**

Physical activity is defined by Caspersen, Powell and Christenson (1985, p.129) as “any bodily movement produced by the skeletal muscles that results in energy expenditure”. Exercise can be described as a subset of physical activity and is structured and repetitive, with a final or intermediate objective, such as the improvement of, or maintenance of physical fitness (Caspersen et al, 1985). According to Myers et al. (2015), more than five decades of epidemiological studies have shown that higher physical activity patterns and cardiorespiratory fitness are associated with better health outcome. According to the World Health Organization (2011), physical inactivity is responsible for an estimated 3.2 million deaths globally (WHO, 2011). As a result, a sedentary lifestyle is considered to be a leading preventable cause of death.

Exercise training is described as perhaps the most physiological and best approach to exploit the adaptive capacity of the coronary vascular bed and to evoke a number of functional and structural changes (Tremblay & Pyke, 2019). At the same time, we know that avoidance of doing physical activity is both described in research (Lochbaum, Jean-Noel, Pinar & Gilson, 2017) and observed in clinical practice (Jonsbu, Dammen, Morken & Martinsen, 2010; Jonsbu et al., 2011; Simonÿ, Dreyer, Pedersen & Birkelund, 2017). For example, Simonÿ et al. (2017) conducted a phenomenological-hermeneutic study of patients’ experiences when they suffered a minor heart attack and participated in cardiac rehabilitation. The authors claimed that the patients found the cardiac disease as a difficult challenge, which lead to vulnerability and helplessness. The results revealed anxiety regarding exercise, encouragement from training along with other patients, and growing confidence in the heart.

Disease-specific exercise guidelines for cardiovascular disease are widely available (Mezzani et al., 2013; Piepoli et al., 2014; Piepoli et al., 2016). However, a recent European (Belgium, Netherland, Germany,

France, United Kingdom, Italy, Spain, Austria and Portugal) study about prescriptions for patients with various cardiovascular diseases reveals significant inter-clinical variance (Hansen et al., 2018).

A significant concern in cardiac rehabilitation programmes is the intensity of aerobic exercise (Mezzani, et al., 2013). Several guidelines and publications include intensity ranges for aerobic training prescription (Mezzani, et al., 2013; Piepoli, et al., 2014). High-intensity interval training involves repeated periods of activity of short duration (bouts), high to severe or severe to extreme intensity exercise separated by brief periods of lower intensity. This has been recommended for improving exercise capacity and for being more effective than continuous exercise (Guiraud et al., 2012; Moholdt et al., 2012; Vanhees et al., 2012; Achttien et al., 2013; Mezzani et al., 2013; Piepoli et al., 2014). However, contradictory results have been presented (Ellingsen et al., 2017), which indicates that more knowledge is needed for recommendations of exercise training for patients with unexplained chest pain.

In this thesis, Study III was part of a larger study, the SYNDEX study, where aerobic high-intensity exercise training was used in patients with chest pain and normal coronary angiogram. Relevant parts of the SYNDEX study will be described on page 28-30 to provide background.

According to Jason, McGannon, Blanchard, Rainham, and Dechman (2015), there is a need for a multidisciplinary approach, as well as more research and regulation in the area of physical activity for patients with chest pain. Jason et al. (2015) state that although medicine of the past focused on population medicine, medicine of the future will focus on the individual. There seems to be a need to further explore the patient's information needs and experiences related to physical activity.

### **3.4 Organization of care for people with (unexplained) chest pain**

In Norway, general practitioners (GP) are usually the first health professional level to attend in case of chest pain, as all persons are listed with different GPs, based on a contract with the municipality. Other health contact options are the casualty clinic, local emergency communication centres or emergency medical communication centres (Burman, 2015). In Norway there are well-defined structural borders between primary and secondary health care services. Only a physician can admit patients to the emergency department. Nevertheless, when ambulance personnel evaluate the patient to have a life-threatening medical condition, the patient will normally be taken directly to the emergency department (Burman, 2015).

Two Norwegian studies (Zakariassen, Burman & Hundskaar, 2010; Bjørnsen, Naess-Pley, Dale, Grenne & Wiseth, 2019) indicate that emergency medicine outside hospitals mainly concerns acute chest pain as the most common symptom. According to Burman, Zakariassen & Hundskaar (2011) the majority of patients with acute chest pain defined as “a red response situation” (an “acute” response with highest priority) were admitted to a hospital for further investigation. However, only a quarter of the patients were assessed pre-hospital to have a severe cardiac heart disease. This illuminates the challenges in deciding the appropriate level of response for patients with acute chest pain (Burman et al., 2011) and the complexity of the illness experience.

### **3.5 Summarising the background to this thesis**

More light needs to be shed on the “black box” of the puzzling condition of unexplained chest pain and thereby more knowledge acquired about living with chest pain. The economic burden of chest pain is high and rapidly escalating. Parallel with the increased body of knowledge about the biomedical bases for unexplained chest pain, challenges to life and

## *Background*

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everyday activities still need to be addressed. Patients' understanding and sense-making in regard to experiences of chest pain with consequences specifically for the level of physical activity seem to be significant factors in everyday life. In addition, a broader view of the person's illness experiences and how signs and symptoms manifest themselves in relation to health need to be taken into account. Such knowledge is vital for the development of health care quality and supportive and preventive programmes and activities for this group of patients.

*Background*

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## **4 Theoretical perspectives**

Here the concept of “person” is described as a basis for this thesis, followed by perspectives on the lived body, capability, vulnerability and uncertainty. We will then take a look at health, including bodily signs and symptoms, illness and disease related to unexplained chest pain.

### **4.1 Person**

The point of departure for this thesis is a perspective wherein the patient is regarded as a whole person with unique experiences (Eriksson, 2001, 2010; Dahlberg & Segesten, 2010). The basis for understanding the wholeness of the person can be related to phenomenological ideas of the life world and lived body (Merleau-Ponty, 2012).

According to Ricoeur (Ricoeur, 1994, Kristensson Ugglå, 2011, p. 248) a person is characterized by being a body, expressing meaning in action, and being in development. A person is thereby responsible for their own actions, also sees such competencies in other persons, and becomes a person in relationship with others (Ricoeur, 1990).

A “person” is seen as being both capable and vulnerable when living in relationships (Ricoeur 1990/94). This implies a movement between being a subject on the one hand, and partly on focusing on the person’s relationships, life context and living conditions in the wider sense on the other (Öhlén & Friberg 2019).

#### **4.1.1 Perspectives on the lived body – significance of experiencing chest pain**

The participants in our studies experienced chest pain, which means something hurt located in the chest. In the words of Merleau-Ponty (2012), every experience is embodied. This means that for me as a

person, the body is my point of view and my way of experiencing and understanding the world.

The philosopher Edmund Husserl introduced the concept of life-world at the beginning of the twentieth century. It is the human being's natural, taken-for-granted everyday world of common experiences (Dahlberg, Dahlberg & Nyström, 2008). The life world is the world that is lived bodily, and through which meaning is constituted. For our study participants, this meant their everyday life situation. The common notion of "a body" is a dualistic notion of the body as an object, but Merleau-Ponty offers a holistic view of the body. We do not have our bodies; we are our bodies. If we return to the participants of this thesis, it is important to address chest pain as embodied.

The ideas of the lived body are worth noting in a study about pain that is unexplained, and where visible signs of the disease are difficult to identify. In the present thesis, a person's individual understanding of themselves, their bodies, and their life situations, and what this means for physical activities and exercise training are in focus.

#### *4.1.2 Capability*

Based on philosophical anthropology – viewing man as a person – Ricoeur (Kristensson Uggla, 2011, p. 229) deals with "capability". The functioning of the individual is the actual achievement through being or doing (Mitra, 2006). Functioning is a way of being or doing, as in, for example, physical activity. Capability is dynamically shaped by interactions between individuals and their environments. The basic idea of the capability approach is to have capabilities for valued functioning (Entwistle & Watt, 2013). This implies what they are free and able to do and be.

This illuminates the conditions that affect health and one's ability to make health choices. For example, getting chest pain can bring

unexpected disruption, for example, in connection to physical activity. According to Prah Ruger (2010), health capability offers promise in finding a balance between paternalism and autonomy by respecting the health consequences individuals face and their health agency.

Functioning is doing or ways of being, such as being physically active – walking, running, hiking. To achieve particular functioning, capability is dynamically shaped by interactions between individuals and their environments, including social relationships. Having capabilities for valued functioning is the basic idea of the capabilities approach (Entwistle & Watt, 2013). Returning to this thesis, the patients are able to do and be, and have reasons to value doing and being.

#### *4.1.3 Vulnerability*

Ricoeur (Kristensson Ugglå, 2011) claims that vulnerability is a constant human experience and condition. From a phenomenological perspective, it is related to our embodied state in particular. In relation to illness, Carel (2009) distinguishes between objective and subjective vulnerability. Objective risks, such as avoiding physical activity, expose people to what is described as objective vulnerability. There is no necessary relationship between what Carel (2009) describes as illness and feelings of subjective vulnerability, as our response to illness varies. According to Gjengedal et al., (2013), vulnerability is an existential phenomenon. Further, according to Purcell (2013), our identities are only complete through our commitment to others. Depending on the situation and cultural context, the degree of vulnerability will vary.

Ricoeur's (1994) reflections on the capable self show there is a lived paradox in autonomy and vulnerability. In his view, a person is both capable and vulnerable, and there is a duality in that. From a phenomenological perspective, it is related to our embodied state in particular.

#### *4.1.4 Uncertainty*

Uncertainty is defined by Mishel (1988) as “the inability to determine the meaning of illness-related events.” Mishel developed the original uncertainty theory to address uncertainty during the diagnostic and treatment phases of an illness, or an illness with a determined downward trajectory (Mishel, 1988). A reconceptualised uncertainty in illness theory was then developed to address the experience of living with continuous uncertainty in either a chronic illness requiring ongoing management or an illness with a possibility of recurrence (Mishel, 1990). Uncertainty is a multidimensional concept and contains various aspects.

There are a number of possible factors which can contribute to unexplained chest pain. According to Mishel (1988), all uncertain situations lack form or structure. Living with unexplained chest pain often means living without an explanation for the pain. McCormick (2002) also claims uncertainty is a multidimensional concept, which in its purest form is a neutral cognitive state and should not be mistaken for its emotional outcomes. Patients may feel emotionally distressed about a situation without having first felt uncertain.

An information-theoretical approach presented by Peters, McEwen and Fristone (2017) defines the essence of stress as uncertainty. In their view, uncertainty is “expected surprise”. This means, in relation to everyday life, that we feel uncertain when we anticipate outcomes will be something other than expected, and that we are unable to avoid surprise. Adamson (1997) and van den Bos (2009) claim there are two characteristics of uncertainty; one being existential and one having clinical aspects. The term ‘personal uncertainty’ is used by van den Bos (2009) and defined as “the aversive feeling that you experience when you feel uncertain about yourself”.

Health professionals who meet patients with unexplained chest pain also live in a space of uncertainty. Simpkin and Schwartztein (2016) claim that physicians, for example, too often focus on transforming a patient’s

narrative into a black-and-white diagnosis that can be categorized and labelled. According to them, uncertainty is generally suppressed and ignored, and this instils in us a sense of vulnerability because of the uncertainty. Being open to patients' uncertainty appears to be important in a study about experiences of living with unexplained chest pain.

## **4.2 Health**

In the early definition of health, The World Health Organization (WHO) (1946) defined it as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. Since then, the meaning of the concept of health has been widened in accordance with WHO's most recent definition. In a study about living with unexplained chest pain, there is a need to embrace a multi-dimensional definition of health. That involves, for example, taking biological, emotional, social and existential dimensions into consideration. Dahlberg and Segesten (2010, p. 62) define health as “a balanced feeling of freedom and vulnerability that constitutes a person's well-being and capacity to pursue minor and major life projects that they value”. Health can be seen as a personal process that is created and lived in daily life. A holistic and humanistic perspective like this focuses on the human as a whole (Eriksson, 2001). Therefore, a biological perspective (Boorse, 1977) on health as the absence of disease is too restricted. This is consistent with my thesis where the perspective is that human beings are unique and must be met as such.

### **4.2.1 Bodily signs and symptoms**

The concepts of signs and symptoms are defined and used in different ways. There is a wide range of concepts surrounding the term 'symptom'. According to Edwards (2008) and Sharpe and Walker (2009), the leading biomedical standpoint uses it in terms of pathology. Brink and Scott (2013) state that the term 'symptom' as an all-embracing

marker of disease may still be widespread in everyday health care practice. The meaning of the term therefore becomes unclear.

According to Edwards (2008) the concept of ‘signs’ can be described as alterations that can be detected through the observer’s senses and denoted by objective biomedical disease markers, for example, positive stress test, abnormal angiography and laboratory tests. Signs are used to refer to pathological changes.

However, in this thesis, the term ‘symptom’ refers to the subjective experience of illness, and something that is not directly observable. According to Dodd et al. (2001), a symptom is a subjective experience and is the most common reason for people to seek care. In this thesis, the participants have symptoms following pain in the chest, but not always objective signs. The person’s awareness of their body is altered and previous functions taken for granted are brought to attention. This is interpreted as a bodily message (Leder, 1990; Malterud, Guassora, Graungaard & Reventlow, 2015). The symptom experience is affected by the perception, evaluation and response to the symptom. Perception is a process of receiving sensory inputs and an awareness of changes in the way an individual feels or acts. Ricoeur (Kristensson Uggla, 2011) describes symptoms as a track, comparing them to a riddle, whereby bodily expressions (verbal, nonverbal) are to be interpreted in relation to the track.

#### *4.2.2 Illness and disease related to unexplained chest pain*

The participants in the studies experience illness even though it is not conceptualized. Illness in relation to unexplained chest pain can be seen as belonging to a pre-medical stage, and thereby not yet described as a disease. The medical anthropologist Leon Eisenberg (1977) describes illness as a subjective feeling indicating that something is wrong in the body and that health is affected. The social scientist, S Kay Toombs

(1993), has used the ideas of the lived body to interpret and understand the existential meaning of illness. She says the meaning of illness is specific to each person. Illness involves the current context, the biological body, and also considerations of future. The experience of illness represents the person's reality and involves their whole existence.

Disease, on the other hand, is described by Eisenberg (1977) as an objective classification of pathophysiological processes. The diagnostic system in biomedicine is based on this statement. Kleinman (1988) similarly defines disease as an "objective biological event" that involves disruption of specific body structures or organs or physiological changes (Mechanic, 1986; Kleinman, 1988). The patients with unexplained chest pain may have signs which can be hard to visualize directly.

A common perception of illness is a subjective experience, which indicates that a possible underlying disease is present. Such ways of thinking can be addressed by both the patient, members of the family or wider social or societal networks. There must be an openness towards perceptions like this in the participants' narratives.

*Theoretical perspectives*

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## 5 Methods

### 5.1 Research design

The overarching aim of this project was to develop knowledge about experiences in relation to living with unexplained chest pain. A descriptive and explorative design (Polit & Beck, 2018) was found to be appropriate (see Table 1). In order to answer the research questions, studies were performed with different qualitative methodological approaches, which remained separate during the analysis phase (Table I). This thesis draws on data from three samples and analysis approaches. Using different qualitative data analyses in the thesis does not necessarily mean that the whole is greater than the sum of the parts (Polit & Beck, 2018). However, it may help to provide a richer account than either approach alone.

Table 1 – Overview of all three studies in the thesis

<b>Studies</b>	<b>Design</b>	<b>Focus</b>	<b>Parti- pants</b>	<b>Data collection method</b>	<b>Analysis</b>
Paper I	Explorative and descriptive (Inductive)	Information needs of patients with unexplained chest pain	7 patients	Interviews	Qualitative content analysis
Paper II	Explorative and interpretive (Inductive)	Meaning of physical activity for people with unexplained chest pain	15 patients	Interviews	Phenomenological hermeneutical approach
Paper III	Explorative (Inductive)	The transitional process persons with unexplained	12 patients	Reflexive diaries and interviews	Grounded theory

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		chest pain undergo while participating in an exercise programme over time			
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## **5.2 Participants and recruitment process**

### **5.2.1 Study I and II**

A purposive sample (Polit & Beck, 2018) of patients was used. Suitable patients attending a cardiac outpatient clinic at a university hospital in Norway who met inclusion criteria were approached to take part during the recruitment phase.

#### Inclusion criteria

- have attended a cardiac outpatient clinic at a university hospital in Norway, previous recruitment
- chest pain, and a cardiologist should have ascertained that the patient’s symptoms had no apparent organic cause
- at least 18 years of age
- able to understand and speak Norwegian

#### Exclusion criteria

- no symptoms of chest pain
- age less than 18 years
- pathological findings from the bicycle exercise test
- not able to understand and speak Norwegian

A symptom-limited bicycle test was given to all eligible participants in the outpatient clinic. They received information about the test results, as well as standard information about risk factors and lifestyle factors related to development of heart disease.

Participants Study I: Participants who met the inclusion criteria were consecutively invited to take part in the study via a letter distributed by the head nurse in the cardiac outpatient clinic. The recruitment of participants continued over a six-month period. Those who were interested in taking part contacted the head nurse. Four women aged between 21-60 years and three men aged between 58-62 participated.

Participants Study II: The participants in Study II consisted of the participants from Study I, with an additional eight patients recruited according to the same inclusion/exclusion criteria as for Study I. These were recruited on the assumption that additional participants would increase variation in data. For Study II, the focus was experiences of physical activity. The head nurse and a nurse at the cardiac outpatient clinic telephoned the patients to invite them to take part in the study. This subsequent selection process continued for 3 months. The second dataset comprised five women and three men, bringing the total to nine women aged between 21-78, and six men aged between 42-65 participating in the study.

### *5.2.2 Study III*

Patients with chest pain who had normal or near normal coronary arteries assessed by coronary angiography at a university hospital in Norway, were eligible for participation. Near normal coronary arteries is defined as stenosis less than 30%. To select participants, coronary angiography was performed using standard techniques.

Inclusion criteria:

- outpatients and patients admitted to the hospital with repeated episodes of exercise induced chest pain.
- normal or near normal coronary angiogram or negative CT coronary angiogram
- age > 18 years
- able to participate in training groups 3 times a week for twelve weeks

Exclusion criteria

- prior myocardial infarction
- serious valve disease
- cancer
- previous radiation or drug therapy for cancer
- musculoskeletal problems making exercise training impossible
- ongoing serious inflammatory disease
- intra cardiac devices
- presumed insufficient acoustic windows because of severe emphysema or gross overweight
- atrial fibrillation
- participation in other ongoing studies
- contrast allergy
- contraindication to adenosine infusion
- vasospastic angina

The lists of patients were checked according to the inclusion criteria first by a nurse, then a physician and finally a cardiologist. Forty patients who met the inclusion criteria were subsequently contacted and invited to an information meeting at the hospital. Seventeen patients met up and received thorough information about the project. All the health professionals contributing to the project presented themselves. Patients had approximately one week to think through the information. Those agreeing to participate were contacted again and invited to a medical investigation approximately 7 days after the information meeting.

Table 2 – Overview of gender and age of participants Study III

Participants	Female	Male	Years of age
Study III	7	5	40–45 1
			46–50 1
			51–55 –
			56–60 2
			61–65 3
			66–70 4
			71–75 1

### 5.3 The settings

#### 5.3.1 Outpatient unit setting Study I,II

The setting for Studies I and II was a cardiac outpatient clinic at a university hospital.

The data collection (interviews) were performed in undisturbed rooms either in the same building as the cardiac outpatient clinic at the university hospital or in a room at the university.

### 5.3.2 Outpatient unit setting Study III

Study III was conducted as part of the pilot project, The Syndrome X-exercise study, SYNDEX: Effect of Aerobic High-intensity Exercise Training on Coronary Flow Reserve, Endothelial Function and psychological function in Individuals with Chest Pain and Normal Coronary Angiogram (Khanmohammadi, Engan, Sæland, Eftestøl & Larsen, 2019).

Study III concerns patient experiences after participating in exercise training as part of an intervention (see below for details). The exercise training took place in a building close to the hospital, in a room equipped with treadmills and screen showing the heart rate observable by the patient and the health professionals connected to this project. There was also a training scheme displayed beside the screen (Figure 1, Paper III). During each training session, music was played on a stereo system. Outside the training room, there was a waiting room with a defibrillator placed on a wall, changing rooms and showers.

Two specialized physiotherapists and three nurses led the training. Physicians who were part of the team were always available. The participants exercised in groups: two groups with four participants and two groups with two participants.

#### 5.3.2.1 Intervention

A short description of the Syndex intervention follows to enhance understanding of the background to Study III. Note that in Study III, only patient experiences of participating in the exercise training were in focus.

##### 5.3.2.1.1 The Syndrome X-exercise study, SYNDEX

The aim of the SYNDEX project was to map the ability of the cardiovascular system to increase blood flow. The hypothesis was that an established exercise plan could improve heart function, which in turn

could lead to less chest pain. The effect of the exercise on mental aspects of the patients was also measured (not part of this thesis). Patients were divided into two groups, one of which participated in a high intensity exercise training programme, while the other (control) group did not participate but had the same follow-up. Training took place three times a week for twelve weeks. Data was generated in the form of blood sampling, echocardiography, measurements of flow-mediated vasodilatation with ultrasound, Doppler of the coronary artery at rest and during full hyperaemia and a 24-hour heart rate registration. Information was also obtained from the patient record. In addition, different questionnaires were used. The main findings of the physiological effect measurement were published in an abstract for the European Society of cardiology Scientific Session, London, UK in 2015.

#### *5.3.2.1.2 A brief overview of the high-intensity exercise programme*

High intensity interval training refers to repeated short sessions of relatively high intensity against 80-90% volume O<sub>2</sub> at 85-95% of maximum heart frequency. Traditionally, high intensity interval training has been used in sport to improve aerobic and anaerobic capacity (Cornish, Broadbent & Cheema, 2011). In the last decade, several randomized controlled studies have shown significant and clinically important physiological adaptations (which means physiology changes after high intensity training) in coronary patients using high intensity interval training (Rognmo, Hetland, Helgerud, Hoff & Slørdahl, 2004; Warburton et al., 2005; Munk, Staal, Butt, Isaksen & Larsen, 2009). Studies of Munk et al. (2009) indicate that high intensity interval training has been shown to be well tolerated by stable coronary patients.

The exercise training programme was designed based on published data in the field (Cosín-Sales, Pizzi, Brown & Kaski 2003; Munk et al., 2009). It was performed in coordination with two experienced physical therapists specialised in cardiac rehabilitation. The programme consisted

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of a twelve-week group-based exercise activity programme. Two trained physiotherapists and two trained nurses took part in each group.

The exercise training sessions lasted for 38 minutes. Each session consisted of a ten minute warm-up period at moderate intensities (60-70% of maximum heart rate (HR), based on the results of an initial exercise test, followed by a total of four intervals at 90-95%  $HR_{max}$  (85-90%  $VO_2$  peak) with 3 minutes of active recovery phases at 60-70%  $HR_{max}$  in between intervals and at the end of the session. The sessions were monitored with individual HR monitors (Polar RS100; Kempele, Finland).

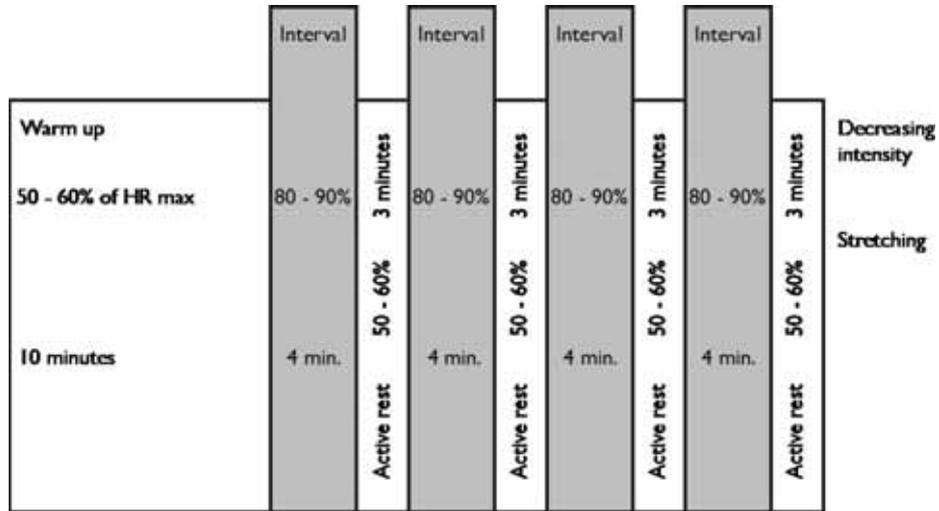


Figure 1 – High-intensity aerobic exercise training programme, HRmax = maximum heart rate. Frequency and duration: three times per week for 12 weeks. Time: Monday, Wednesday and Friday at 7:30 am or 14:30 pm.

#### 5.4 Data collection

Data consisted of qualitative interviews and diary texts. The data collection is described in detail below. The data collection periods are shown in Table 3.

Table 3 – Overview of periods of data collection

Studies	Study I	Study II	Study III
Period of data collection	May 2010 – June 2010	May 2010 – June 2010 and October 2012 – December 2012	November 2013 – June 2014

#### *5.4.1 Qualitative interviews with patients Study I and II*

Interviews were conducted with patients who attended the cardiology outpatient clinic and met the inclusion/exclusion criteria. I moderated, audiotaped and transcribed the interviews verbatim according to the participants' experiences of the challenges related to information needs (Study I) and physical activity (Study II) (Polit & Beck, 2018).

The interviews lasted for approximately one hour. The interviews in Study I and the first seven in Study II were semi-structured individual interviews in accordance with Kvale and Brinkmann (2009). An interview guide was used in Study I (see Interview guide, Study I). The participants were encouraged to describe their experiences of living with unexplained chest pain and information needs. In Study II, physical activity was emphasised among these. The interviews were in narrative form and conducted as a conversation in which the informant was encouraged to talk freely (Kvale & Brinkmann, 2009). In the raw data of the first seven interviews, a need for more information about physical activity was identified. Based on this, we made the decision to probe deeper into this need.

As the basis for Study II, text sequences related to physical activity were identified from the first seven interviews. The next eight interviews in Study II were more open ended in accordance with Mishler (1991). The participants were encouraged to speak more in depth about what it was like to be physically active. They were invited to talk in their own words, and were also asked follow-up questions such as: "Could you expand on that?" and "Could you give more examples from daily life?" (Mishler, 1991). All interviews were transcribed verbatim. Non-verbal expressions such as laughter, crying and pauses were noted in the transcripts (Mishler, 1991).

#### *5.4.2 Diaries and interview data Study III*

Data were collected during and after the exercise-training programme.

#### **5.4.2.1 Diaries**

The participants were asked to write a diary about their experiences of training during the exercise programme and one, two and three months after training was finished. The diaries were semi-structured (Bartlett & Milligan, 2015), which means they are designed to encourage the diarist to write a more detailed temporal narrative, often around a loosely structured set of themes (Bartlett & Milligan, 2015). The purpose of this design is to gain a deeper understanding of a person's actions, experiences, thoughts and emotion around a particular topic. According to Bartlett and Milligan (2015), a key advantage of using diaries is that it removes the researcher from the point of data capture, which affords participants private space to record their views. This data collection method is especially useful for sensitive or emotive data (Bartlett & Milligan, 2015). In addition, it can provide more accurate documentation than only conducting a qualitative interview, as reflections are usually recorded shortly after the event. The following questions were written in textual form in the diary: Please tell us how your chest pain has been this past month, Please tell us how your chest pain has affected your daily life in the past month, Please tell us what the group you are participating with has meant to you over the past month.

#### **5.4.2.2 Interviews**

In addition, the participants were interviewed after the programme about their experiences of having taken part in a high intensity physical exercise programme. The interviews lasted from 40-120 minutes. These interviews were based on the diaries and carried out after the exercise programme was finished. The diaries contributed to the patients remembering experiences of training during the exercise programme. In the interviews, the participants were asked to expand on what they wrote in their diaries. In addition, the interviews were carried out before the participants had medical tests after participating in the programme. The participants were invited to talk in their own words, and were also asked

follow-up questions, such as: “Could you expand on that?” and “Could you give more examples from daily life?” (Mishler, 1991). The interviews were open conversations, following the participants’ line of thought. I moderated and transcribed verbatim all the interviews. Non-verbal expressions such as laughter, crying, and pauses were noted in the transcripts (Mishler, 1991). Directly after each interview, I wrote down shorter meanings or supporting words. I read through this and made notes.

## **5.5 Analysis of data**

Three different qualitative methods of data analysis were found appropriate in answering the research questions in the thesis (see Table I). The analysis included qualitative content analysis (Graneheim & Lundman, 2004), phenomenological hermeneutical analysis (Lindseth & Norberg, 2004), and analysis according to classic grounded theory (Strauss & Glaser, 1967; Glaser, 1978).

### **5.5.1 Content analysis (Study I)**

A qualitative content analysis was performed and the procedures suggested by Graneheim and Lundman (2004) were found to be appropriate. Graneheim and Lundman (2004) make a distinction between manifest and latent qualitative content analysis. In the first manifest analysis, it was asked if any information needs could be identified and related to unexplained chest pain, and if so, which. The text was read, and all text about information needs was marked. The meaning units representing the questions asked from the interview guide were systematically chosen and coded before condensing the text and grouping a list of information needs. Subcategories were then identified and compiled.

Analysis of the text deals with the content aspect (Graneheim & Lundman, 2004) and describes how the participants talked about their

information needs. The analysis also deals with the relationship aspect (Graneheim & Lundman, 2004) and involves an interpretation of the underlying meaning (latent level) of the information needs. In the present analysis, there is both a manifest and latent level. To conclude the analysis, the author and co-authors reflected together on its entirety.

Table 4 – Illustration of the analysis process in Study I

Condensed meaning unit	Category	Subtheme	Theme
<p>They don't think of each person as having individual questions when giving information</p> <p>The examination in the clinic which found unexplained chest pain left me with many questions, but he (cardiologist) would not listen to my story</p> <p>Didn't have time to ask questions</p> <p>They said you could ask, but there was no room for it</p> <p>People don't talk about it (unexplained chest pain)</p> <p>Strange that they don't get (together) those who have the problems to talk with others</p>	<p>Not being seen as a person</p> <p>Lack of time for asking questions</p> <p>Alone with the problems</p>	<p>Experiencing lack of focus on individual problems</p>	<p>Experiencing unmet information needs</p>

### 5.5.2 Phenomenological hermeneutics (Study II)

A phenomenological hermeneutic approach (Lindseth & Norberg, 2004) inspired by Paul Ricoeur's philosophy (1976) was used in analysing the interview data. According to Ricoeur (1976) the aim is to interpret the meaning of the text and describe what is hidden. To create knowledge about human experience, people communicate their lived experiences and transfer these into textual form. Hermeneutical ideas of a circular movement between understanding and explaining the text guided the analysis and rigor considerations. The analysis included a three-step method (Lindseth & Norberg, 2004): naïve interpretation, structural

analysis and comprehensive understanding. The naïve reading gave us a sense of the whole and formed a first naïve understanding of the phenomenon. We wanted to focus on the essence of the understandable meaning of the experiences of physical activity for people with unexplained chest pain. The naïve interpretation guided the structural analysis. The data were first systematically examined to gain a deeper understanding of the content of the interviews before the meaning units were identified and extracted from the text. The units were subsequently compared and critically reviewed in relation to the naïve understanding. The text was condensed into subthemes and themes. According to Ricoeur (1976) and Lindseth and Norberg (2004), the interpretation theory was the main inspiration for opening the way into the hermeneutical circle by moving through the methodological steps. In the last part of the interpretation, the main theme, themes and sub-themes were summarized and reflected on in relation to the research question and the context of the study (Lindseth & Norberg, 2004). The results were formulated in everyday language as close to the lived experience as possible. This interpretation of the comprehensiveness was formulated as a “deepened meaning”.

Table 5 – Illustration of the analysis process in Study II

<b>Meaning Unit</b>	<b>Condensed Meaning Unit</b>	<b>Subtheme</b>
<p>No, I'm the kind of person, in one way, that on another occasion, when I was taking one of the kids up a (clears her throat) really steep hill, I don't give up (smiles a little), because I'm going to the top, right? And then I had one of those episodes [of chest pain] again. But I could have done with trying to stop and catch my breath a little.</p> <p>Because I'm a bit like, I might seem very calm on the outside, but I'm not completely calm, you know. I think about everything beforehand and think the worst, as a mother, and you know. Now I don't have small kids</p>	<p>Being a certain kind of person</p> <ul style="list-style-type: none"> <li>•• not giving up</li> <li>•• being susceptible to anxiety</li> </ul>	<p>Considering/reflecting upon myself as a person</p>

but I do have people in the house and then I think I have to make everyone happy – I mean for me in a way. So it gets very stressful.		
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### 5.5.3 Grounded Theory (Study III)

Grounded theory was used to generate a theory that accounts for the activities/actions of patients with unexplained chest pain participating in a high-intensity exercise programme (Strauss & Glaser, 1967; Glaser, 1978). As pointed out by Glaser (1992) in classic grounded theory, openness is of significance, as well as freedom from preconceived knowledge to see and discover the most relevant concepts in data while avoiding influencing theory (Glaser 1992). Within this, we tried to understand the complexity of what is going on, as described by the participants in their diaries and interviews. I took notes after each interview. Data collection and analysis took place simultaneously. The ongoing analysis of the reflective diaries directed further data collection through the interviews of each participant.

Rather than fragments, entire incidents must be considered in the analysis (Glaser, 1978). Open coding, selective coding, memo writing, theoretical coding and sampling were used in the analysis. Each level of coding moved the analysis towards increased levels of abstraction during the comparative analysis. By comparing data on different levels of abstraction, the analysis was validated. Further, validation was ensured by reading the developing pattern of the grounded theory in relation to all data.

One example is the subcategory “becoming a more capable person”. Experience of participating in the exercise training programme enabled participants to become more capable. Through participation, these individuals were brought into an experience of distressing uncertainty, but they moved on to the process of alleviating distress by letting go and

being reassured. Despite the chest pain, the participants experienced confidence in physical activity. They moved from uncertainty about physical activity and chest pain to experiencing physical activity as something giving them strength. The participants focused on making sense of recent events. They reflected over their experiences of symptoms and their knowledge of the body and mind. Most of the participants expressed feeling much better, and talked about seeing more possibilities in life. For example, one wanted to go back to work after having been on sick leave and disability benefits for two years. Becoming more capable created possibilities. Most participants felt better than they expected after taking part in the exercise training programme. They experienced personal growth and gained an enhanced outlook on life. One expressed it as ‘coming out of the quagmire’. Another patient said:

‘I am also a bit uplifted because I have experienced fewer symptoms of . . . I think . . . activity in the heart region or . . . I can’t define it . . . but that thing (chest pain – author’s comment). I haven’t experienced/sensed it as much now when I train. So I believe that . . . I think it (the training – author’s comment) has managed somehow to get these symptoms away in one way or another’.

The progress of the analysis was discussed within the researcher group. The reflections notes were read and the interviews listened to several times in order to discover a variety of perspectives. Selective coding was carried out by transferring a limited selection of codes over to larger parts of the collected data. The core category “confronting one’s vulnerability” was identified in the theory under development.

#### ***5.5.4 Strength and limitations of the methods used***

In line with Polit and Beck (2018) the research designs were selected appropriately to answer the research questions by allowing a variety of strategies.

In the complex debate about quality in qualitative research, Lincoln and Guba (1985) suggested standards for trustworthiness of qualitative research that parallel the standards of reliability and validity in quantitative research (Polit & Beck 2018). The five criteria as suggested by Lincoln and Guba (1985) are used for evaluating the trustworthiness of the inquiry: credibility, dependability, conformability, transferability and (added to their framework at a later date) authenticity (Polit & Beck, 2018). These criteria were considered during the study of this thesis.

*Credibility* refers to confidence in the data and its interpretations. It involves conducting the study in such a way that the believability of the findings is strengthened, and demonstrating the credibility in research reports (Lincoln & Guba, 1985; Polit & Beck, 2018). In order to become familiar with current practice for investigating patients for chest pain, I attended an in- and out-patient clinic for a couple of weeks before doing the interviews.

We tried to invest sufficient time in collecting data to gain an in-depth understanding of exploring information needs of patients living with unexplained chest pain (Study I). In Study II, the experience of the meaning of living with unexplained chest pain and physical activity was deepened. In Study III, an accurate representation of the participants' experiences facilitated the transition process, which in turn generated a common thread from research questions and analysis to describing the results. The work was critically appraised by other PhD students and co-researchers in seminars during the whole research process. I also received comments regarding the presentation of the results in national and international conferences, and this made me reflect more critically throughout the different research phases.

Selected quotations from the different studies were chosen to validate the analysis. According to Glaser (1978), quotations are not recommended, and can interfere with the analysis, as these excerpts do not in themselves explain the general behaviour, social interaction or phenomena being

investigated. Nevertheless, quotations are used here with the intention of following the evolution of the results.

*Dependability* concerns whether the conditions and data are stable over time (Lincoln & Guba, 1985; Polit & Beck, 2018). Our selected participants were individuals experiencing unexplained chest pain and who also met the other inclusion criteria. The recruitment processes was the same for Studies I and II, using a purposive sample. We assumed participants had lived experiences, which was important as a basis for answering the research questions. Seven individuals agreed to participate in Study I, with an additional eight in Study II bring the total to fifteen. According to Malterud, Siersma and Guassora (2017) qualitative interview studies may benefit from sampling strategies by shifting awareness from the number of participants in a study to the contribution of new knowledge from the analysis. Malterud et al. (2017) further claim that a lower number of participants is acceptable when information power indicates rich information from the sample. We argue that the data in the different studies in the current thesis are rich, even if the participants are few.

In Study III, only those able to participate in exercise groups three times a week for twelve weeks could participate. For this to happen, there were also geographic restrictions on who could attend. The self-selection strategy may have biased the results, as participants might have been too optimistic about what they could manage at the start. Additionally, the number of participants was predetermined. There are specific procedures in grounded theory for theoretical sampling. An ongoing deductive process determines where and how to collect data, and who can comment on this, based on the initial analysis and coding.

In the present thesis, the research process has hopefully been presented in a way that enables the reader to follow the different steps, as well as the logic of and reasons behind the concluding results. International journal referees have also reviewed all three papers before publication.

*Confirmability* considers the data, the interpretation of the data, the studies' grounding in the participants' voice and conditions (Lincoln & Guba, 1985; Polit & Beck, 2018). In the present thesis, the description of the theoretical perspectives, data analysis and main results are intended to fulfil the criterion of confirmability. Issues regarding the selection of the most suitable meaning units, sets of themes and codes were discussed in meetings with co-authors, seminars with doctoral students, and in the research group. We focused on establishing agreement between the different levels of analysis along with our reflections and preunderstanding. Citations have been selected to give the participants a voice, and to allow the readers to follow the analysis process.

I am a registered nurse with further training in psychiatric nursing and many years' experience of clinical practice. I have a Master's degree in health science. In addition, I have worked as a university lecturer, teaching students to become health professionals, mainly nurses. My preunderstanding is important, as my previous education and relations with patients and students have given me valuable insight into the daily life of patients experiencing pain, as well as the experiences of other health professionals. I am trained in dialoguing with patients, which was valuable in interviewing the participants in all three studies. At the same time, I had to be conscious not to let my preunderstanding influence my understanding of the phenomenon. Dahlberg et al. (2008) uses the term "bridling". This represents more than suspending the preunderstanding and contains three aspects. The researcher has to be aware of their preunderstanding – if they are not, personal beliefs and theories may mislead the understanding of meaning, thus restricting the openness of the research process.

According to Dahlberg et al. (2008) what is indefinite must not be made definite. The interviews were set up with room for deepening the phenomenon experienced, as were the diaries (Study III). Dahlberg et al. (2008) further claim that the interviewer must strive to direct the energy

into an open and respectful attitude, which allows the phenomenon to represent itself. I endeavoured to stop preunderstanding from affecting what was happening in the here and now. I strove to practice “bridling” in all aspects related to the studies.

The challenge of classic grounded theory (Straus & Glaser 1967; Glaser, 1978) may be that it can appear unlikely or impossible to prevent previously absorbed theoretical knowledge from affecting theory development process topics. Study III is based on Studies I and II. Within this lie previous literature reviews before commencing Study III. Nevertheless, we have used this method, as to our knowledge there are no previous studies of the transition process patients with unexplained chest pain undergo while participating in a high-intensity exercise training programme.

*Transferability* refers to the extent to which the findings can be transferred to other settings or groups. Our responsibility as investigators is to provide sufficient descriptive data that enables the reader to evaluate the applicability of the data to other contexts (Lincoln & Guba, 1985; Polit & Beck, 2018). The aim of my thesis was to include relevant participants who could make an important contribution to the understanding of the experience related to unexplained chest pain. The results in the present thesis took into consideration the participant context, data collection and process of analysis. This means similar populations, similar situations, and similar phenomena. Dahlberg et al. (2008) claim that practising human science research is a search for knowledge that goes beyond the concrete individuals and their personal experiences. In our studies, the patients were asked for experiences related to information needs and physical activity. With follow-up questions, they were encouraged to deepen their descriptions.

According to Dahlberg et al. (2008), human science research transferability must nevertheless be problematized as complex. But it is also about seeing the relationship between the results of the study and its

context, and how, for example, unexplained chest pain appears in the context of being physically active.

*Authenticity* considers the extent to which researchers are invited into the participants' experiences (Lincoln & Guba, 1985; Polit & Beck, 2018). In the interviews and diaries, we endeavoured use the participants' experiences as closely as possible, with an emphasis on understanding the lives of people with unexplained chest pain according to their information needs and physical activity. Mood, feeling, experience, language and contexts are therefore described. Glaser (1978) discourages transcription of data and audio recordings, as it can interfere with and inhibit sensitivity and creativity in the research process. The analysis was first performed according to Glaser's recommendations but as I am a relatively new to research, I repeated the analysis after transcribing the data, as a validation exercise.

The present thesis employs both qualitative interpretative content analysis (Paper I), phenomenological hermeneutic analysis (Paper II) and grounded theory (Paper III). Methodological considerations often require us to distinguish between philosophical and methodological approaches. The most obvious differences between content analysis and phenomenological hermeneutics are that the first has no obvious connection to a philosophical tradition, while phenomenological hermeneutics is grounded within this. Both methods have an obvious interpretative aspect, although this is traditionally a characteristic of phenomenological hermeneutics. Likewise, in interpretative content analysis, the interpretation focuses on revealing both the manifest and the latent content of the text (Graneheim & Lundman, 2004). Despite the different origins of the approaches mentioned above, both consist of several factors that are compatible with each other for analyzing human expression of lived experiences.

The overall aim in this thesis was to explore and describe experiences related to living with unexplained chest pain. We searched for linking of

knowledge claims, results and interpretation results in the data. This is all about establishing trustworthiness.

## **5.6 Ethical considerations**

Approval was given from the Regional Ethic Committee prior to commencement of the study Part I (2009/2243-7), and for part II (2013/98). The study was approved by the regional ethical committee and performed in accordance with the Helsinki Declaration. All patients signed informed consent from before participating. The patients who met the inclusion criteria and were invited to participate in this study have been assured of anonymity and confidentiality and the option to withdraw at any time. Participants received oral and written information about the aim of the study. The information provided to patients before participation are presented in Appendices III.

People experiencing unexplained chest pain may experience a considerable burden of suffering. The “heart” as a metaphor is widely shared and found in the earliest known writings in ancient language. According to Sheridan (2018), this suggests that it most likely arose from the universal experience of cardiac activity. This was in response to emotion, exercise and mental activity due to the heart’s autonomic regulation by the brain. Sheridan discusses whether the advances in cardiovascular science have contributed to displacing emotional meanings formerly attributed to the heart, thereby downplaying their importance in human experience.

Participating in these studies may provoke difficult feelings and thoughts. Based on these concerns, some participants were encouraged to contact me or other health professionals, if needed. I called the informants twice after the interview to make sure they were well. Further follow up was not needed. Conversely, the participants replied they experienced the interview as a support in their daily life.

One may assume that patients who are willing to participate may be a particular group of people with unexplained chest pain. This could possibly be people who are managing well, and therefore willing to discuss their daily life. On the other hand, it could also be people experiencing challenges in daily life, who see participation in the study as a way of getting more assistance from health professionals. This might lead to bias in terms of whether the studied population and thereby the results represent the experiences of most people living with unexplained chest pain.

There might also be bias in that people were asked by health professionals to participate, and were dependent on them for potential further follow-up. For example, in Study III, a professor of medicine or a physician requested individuals to participate. The participants may have felt dependent on them for further follow up, even though it did not appear that way. However, further follow up was not envisaged, and this may thus minimise any bias.

There was a larger proportion of women participating than men, but this reflects the differences in prevalence of chest pain between the sexes (Safdar et al. 2018a; Bjørnsen, Naess-Pleym, Dale, Grenne & Wiseth 2019). It has been identified that women frequently experience a wider range of cardiac diseases, which includes microvascular and endothelial dysfunction (Garcia, Mulvagh, Merz, Buring & Manson, 2016). According to Safdar et al. (2018a) women were four times as likely to have coronary microvascular dysfunction as men. Nevertheless, in a Norwegian study (Bjørnsen et al. 2019) of patients arriving to the emergency department, there were more men having chest pain, also of patients having non-specific chest pain. However, in general, there is a larger proportion of women (Safdar et al., 2018a; Bjørnsen et al., 2019).

## *Methods*

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## 6 Results

The main findings of the three studies constituting this thesis are presented in the following section. Paper I concerns the information needs of patients with unexplained chest pain and how these needs were met by health professionals during medical consultations. Paper II concerns the physical activity experienced by patients with unexplained chest pain in daily life. Paper III describes the experienced transitional process these patients undergo while participating in an exercise-training program over time.

### 6.1 Study I

#### *Exploring the information needs of patients with unexplained chest pain*

The aim was to describe and explore the information needs of living with unexplained chest pain.

A qualitative design was used. Data were collected by means of seven individual interviews with four women and three men. The interviews were analysed by qualitative content analysis.

The results are described in two subthemes: “experiencing lack of focus on individual problems” and “experiencing unanswered questions”. These were further abstracted under the main theme “experiencing unmet information needs”.

The conclusion is we suggest that existing models of consultation be supplemented with a person-centered approach to meeting patients’ beliefs, perceptions, and expressions of feelings related to experiencing unexplained chest pain. This is in line with a biopsychosocial model with active patient participation, shared decision-making, and

multidisciplinary approach. Such an approach is directly within the domain of nursing, and aims to take into account patient experience.

## **6.2 Study II**

### ***Unexplained chest pain and physical activity: balancing between existential uncertainty and certainty***

The aim of the study was to achieve an understanding of the meaning of physical activity for people with unexplained chest pain.

Fifteen people (nine women and six men) were interviewed and analysed using a phenomenological hermeneutic approach.

The results revealed four themes: “awareness of the influence of previous life experiences on the decision to be physically active”, “awareness of unanswered questions related to physical activity and unexplained chest pain”, “awareness of intertwinement of body and mind”, and “awareness of physical activity as a source of personal growth”. Comprehensive understanding was formulated as “being physically active while living with unexplained chest pain means balancing between existential uncertainty and certainty.”

The findings are discussed in relation to capability. It is suggested that health professionals adopt a person-centered approach.

## **6.3 Study III**

### ***Confronting one’s vulnerability – patients with chest pain participating in a high-intensity exercise programme***

The aim of paper III was to achieve an explanation for the transitional process these patients undergo while participating in an exercise-training programme.

Method: Three times a week for twelve weeks, twelve patients (seven women and five men) participated in a high intensity aerobic exercise training programme supervised by physiotherapists and nurses. The data collection is based on diaries and interviews about the experience and analysed according to the principles of classic grounded theory.

Results: The main core category is identified as “confronting one’s vulnerability” and three subcategories: “balancing existential uncertainty”, “transforming bodily perceptions” and “becoming a more capable person”. The transition is described as a process of becoming more capable.

Health professionals should be aware of the significance of high-intensity exercise training for people with unexplained chest pain and of the underlying dimension of vulnerability.

#### **6.4 Summary of the results**

The aim of this summary is to develop increased understanding of the results. Study I described the uncertainty as exploring the information needs of patients with unexplained chest pain. Uncertainty emerged from unanswered questions, as well as experiencing lack of focus on individual problems. The results also revealed additional aspects of uncertainty related to physical activity.

The interpretation of this experience implies receiving information about the chest pain. The participants were uncertain whether the chest pain was a sign of disease and wanted to meet professionals with a listening attitude. All this provided the potential to create a relational space with the possibility of the patients’ voice becoming manifest in the dialogue.

In paper II, an existential uncertainty related to the chest pain and physical activity was identified. The results were interpreted as balancing between existential uncertainty and existential certainty. The meaning of chest pain related to physical activity was deepened, as the patients

became aware of the influence of previous life experiences. They had unanswered questions related to chest pain and physical activity but experienced an intertwinement of body and mind, with physical activity as a source of personal growth.

In Study III, participating in a high intensity exercise programme revealed a transitional process whereby vulnerability was confronted under safe and supportive circumstances. Throughout the process, patients had to balance their existential uncertainty. For the participants, bodily perceptions were transformed in relation to chest pain and they experienced becoming more capable persons. Considered as a whole, Study I revealed uncertainty related to unanswered questions and lack of focus on individual questions, while Study II highlighted existential uncertainty related to chest pain and physical activity as a balancing act between existential uncertainty and certainty. In Study III this uncertainty was confronted. The training programme can be understood as an experience that changed the person's understanding of what he or she as an individual can and has courage to do. It can also be understood as utilizing the experience to test something you previously felt uncertain about.

## **7 Discussion**

The overall aim of this thesis was to explore and describe experiences related to living with unexplained chest pain. The chest pain related to physical activity were unpredictable in balancing life.

The results can be further interpreted as “chest pain – a subjective feeling of illness”, “confronting uncertainty in relation to health experience”, and “development of patient capability”. This will be discussed in this chapter in the light of theoretical approaches and research and conclude with a description of possible implications for clinical practice and further research.

### ***7.1 Chest pain – a subjective feeling of illness***

The phenomenological ideas of the lived body form one basis of understanding the wholeness of a person. According to the results, the participants in this thesis were aware of intertwinement of body and mind (Study II). They were aware of the influence of previous life experiences on the decision to be physically active and physical activity as a source of personal growth (Study II). Toombs (2004) claims that the prevailing biomedical model of illness and the overriding focus on physical pathology gives priority to the well-functioning of the physical organism. Toombs (2004) is critical of this way of reasoning. Within this lies an assumption that if the body functions well, so does the person. This can be interpreted as the focus primarily being on assessing signs, as in the case of this thesis, of heart disease as the most accurate measure of wellness. A biomedical focus on observable signs, can, according to the results (Study I,II,III) disrupt functioning on a personal level and within this, the participants’ daily life. Expressed in another way, there is a risk that the patient’s illness narrative will be regarded as of minor interest in different kinds of medical consultations. As some participants described in Study I, they did not feel that the health professionals

listened to their individual history of pain. Although the bicycle tests came out negative, the participants were not reassured. They experienced lack of focus on individual problems, and were not seen as “a person” as suggested by person-centered approaches (Ekman et al., 2011; Ekman, 2014; McCormack & McCance, 2006; McCormack & McCance 2016). They felt they were alone with their problems.

The experience of unexplained chest pain influenced the participants’ daily life and living (Study I,II,III). This can be interpreted as pain incorporated in daily life. Living with unexplained chest pain represents a distinct way of being in the world. This is a way of being that affects the participants’ sense of self, the ability to exercise control and relationships with others (Study I,II,III). This is in line with Merleau-Ponty (2012) who says every experience is embodied, and Toombs (2004) who claims that the clinical goals must be broadened to encompass the project of assisting patients to live well in the face of ongoing bodily limitations. The trajectory of unexplained chest pain culminates in a way of living where illness becomes one with the life history (Kleinman, 1988; Kristensson Uggla, 2011). Following Kleinman (1988), the consistent existence of chest pain over a period of time, as well as transformations, such as experiencing being stronger and more capable, then lead to the awareness of the meaning of the illness. The participants in this thesis were uncertain about how to be physically active in a safe way (Study I, II). Study III indicates that participating in a high-intensity exercise programme can be one way of confronting and broadening the way of living with chest pain.

In Studies I and II, a cardiologist had ascertained there were no apparent organic causes for the patients’ chest pain. Nevertheless, patients felt the same chest pain as before the tests in the cardiological outpatient clinic. Chest pain was their subjective experience, indicating that something was wrong. This caused them to balance between existential uncertainty and certainty, as described in Study II. This means they required more information to be able to confidently assess whether it was safe and good

for their health to do physical activities. Health professionals must be prepared to meet both verbalized and more implicitly posed information needs. This is in line with the critique put forward by Marcum in his book: *Humanizing Modern Medicine: An Introductory Philosophy of Medicine* (2008). Marcum claims that physicians and other health professionals have mostly adopted a view that disease is conceptualized exclusively in terms of the physical body. This also often involves the subjective experience of the patient being discounted and viewed as unreliable or irrelevant to medicine (Marcum, 2008). The significance of seeing the person as a unity of body and mind is put forward. According to Merleau Ponty (1968), the patient is situated in a lifeworld as an embodied subject. The body orients the patient to the world around them by means of their chest pain. This can be understood as the patients' existential concerns being associated with the experience of chest pain: in observing their bodies, their heartbeat, and chest pain, they reasoned with themselves as to how to understand this in relation to their bodily sensations.

According to Heggdal (2015), there is a lack of tools for bridging theory and practice through research. Bodyknowledging theory (Heggdal, 2003, 2008) asserts that individuals living with health problems over time possess bodily knowledge that constitutes coping, recovery and health. Heggdal, Oftedal and Hofoss (2018) claim that a person-centered approach in bodyknowledging programmes substantially improve wellbeing and the ability to recover in chronic illness. This can be understood in relation to the participants' desire to meet professionals with a listening attitude (Study I), and in creating relational space where the patients' voices are heard.

Pain perceptions are neither purely mechanical, physiological nor psychological (Zaccagnino & Nedeljkovic, 2017). The patients in Studies I and II experienced chest pain but were told there was no apparent coronary cause for the pain. They expressed uncertainty about clinical aspects marking the diagnosis and treatment of disease, and for

them, this meant having less information than they would have liked (Study II). This can be understood in relation to Kristensson Uggla (2011), who discusses three levels of subordination. Firstly, in connection with health professionals, patients can be regarded as being institutionally subordinated. Hospitals are mainly hierarchically organized institutions, with the patients at the lowest level. Secondly, a patient's life situation with uncertain chest pain can be connected to a threat to health and life, and with this comes existential subordination. Thirdly, patients seek health care as they are in need of assistance, knowledge and understanding, and this often intrinsically puts them in cognitive subordination.

There must thus be awareness from the perspective of the professionals that there is a difference between observable clinical signs and the patients' subjective feelings of illness, often expressed as symptoms. If there is lack of awareness of this way of thinking, the often hierarchical hospital culture can contribute to disintegration in the unity of the lived body, as perceived by the patient. This is comparable to what Kristensson Uggla (Ricœur & Kristensson Uggla, 2011) describes as "institutional subordination" and can contribute to a sense of disorder, which permeates the patients' world (Toombs, 1994, 2004). This can further be related to the ideas of Svenaeus (2011), who describes illness as "unhomelike being-in-the world", meaning there is something foreign that permeates the ill life.

## ***7.2 Uncertainty in relation to unexplained chest pain***

The results from this thesis indicate that physical activity (Study III), as experienced by the participants, seems to change understanding of what the person can and dares to do. This is something professionals must address. However, according to the overall aim, in this section we will discuss the perspective of the patient who is experiencing chest pain. There are several ways in which the thesis points to patients' need for

knowledge and understanding related to living with unexplained chest pain. Study I indicates there are unmet information needs. Further, Study II reveals information needs specifically in relation to being physically active. As shown in Study III, bodily perceptions seemed to be transformed for patients participating in the high intensity exercise training, as they reflected upon what happened in the body during the training sessions and afterwards. Participants seemed to change their way of thinking or talking about the chest pain. This points to the need for openness to differences in expressing knowledge needs. If we as health professionals fail to address the meaning of chest pain for the patient, it influences not only the person, but also the quality of care and patient safety.

The participants were searching for particular certainties in handling their uncertainty in chest pain. Unexplained chest pain is an idiopathic disease in which existential uncertainty is central. Idiopathic conditions arise spontaneously or from an unknown or obscure cause. The participants in Study II strived for certainty, being existential in nature. van den Bos (2009) describes self-regulation and existential sense-making as corresponding to the importance of clarifying beliefs in relation to the balancing act for persons with unexplained chest pain.

It is important to listen to patients' anxiety and fear, both in relation to the examination and to how they manage their everyday life at risk (Study II). As suggested in Study II, health professionals should be open to discussion as a structured part of the medical consultation with patients regarding exertion in daily life. Additionally, they should be aware of the significance of high intensity exercise training for people with unexplained chest pain and the underlying dimension of vulnerability (Study III).

The findings from this thesis show that living with unexplained chest pain affects health in several different ways. Health is here understood as a balanced feeling of freedom and vulnerability that constitutes a

person's well-being and capacity to pursue minor and major life projects that are valued by the person (Dahlberg & Segesten, 2010, p. 62). According to Ricoeur (1992) and Hetteima (2014), vulnerability and autonomy support each other. As the participants described, experiences of uncertainty affected their life situation. Some had experienced chest pain for several years and said there were times when the illness was in the foreground and other times when they felt well and consequently healthier to a greater extent. However, they were not in a state of complete physical, mental and social well-being, and not merely in the absence of disease or infirmity, as per the WHO definition of health (1946, 1986, 2009). Parallels can be drawn with the results of Study II, where the participants balanced between existential uncertainty and certainty. The uncertainty was related to doing physical activity and seen by the participants as a threat to health and life. However, at the same time, physical activity was seen as improving health and life (Study II). If we take into account Dahlberg and Segesten's (2010) definition of health as a balanced feeling of freedom and vulnerability, then the life situations of the participants in this thesis perhaps cannot be defined as healthy. On the other hand, different kinds of physical activities promoted feelings of well-being, as described by the participants. Thus, doing physical activity can be interpreted as exposing the participants to vulnerability, but at the same time, challenging existential uncertainty.

Beliefs related to having or acquiring a heart disease were reformulated, and there was reflection on thoughts about physical activity as being good for the heart (Study II, III). The participants expressed that they were able to pursue minor and major life projects that were of value to them personally (Study II, III). For example, they talked about going hiking as they did before participating in the physical training programme. This points to some kind of freedom against the background of being vulnerable, as their chest pain could intensify, thereby perhaps increasing feelings of uncertainty. Participating in the high intensity exercise programme, which was the focus of Study III, seemed to

promote and restore health in the sense the participants became stronger and fitter. It can also be interpreted as easing their suffering. In Study II, the participants were aware of the influence of previous life experiences on the decision to be physically active. According to Eriksson (2001), health is linked to acting and certain ways of acting. One interpretation is that the patients' experienced wellbeing, and the capacity to pursue valued life projects was linked to physical activity (Study II) and influenced experience of health (Study II, III).

Another aspect related to the experience of health is put forward by Dahlberg and Segesten (2010), as existential vitality is necessary to reach health. This can perhaps be understood in relation to Eslick, Koloski & Talley's (2011) study about sexual, physical and verbal/emotional abuse and unexplained chest pain. A history of emotional/verbal abuse is a risk factor for getting unexplained chest pain. Over forty percent of people with unexplained chest pain in their study reported a history of abuse. Dahlberg and Segesten (2010) enquire whether the fact that we as persons often have difficulties in speaking about our existential pain means that we have to attribute it to an illness category to make space for it in daily communication. If we go back to the research of Eslick et al. (2011), this highlights the need for health professionals to be aware of a possible history of abuse in this group of patients and warrants the need for more research into this area. The health personnel must be observant and identify patients' different bodily expressions (verbal, nonverbal) to support and strengthen resources for health. In accordance with this thesis, the results can be interpreted as experienced improvement in health, as the participants felt better and stronger (Study III). They experienced a difference in fitness and mood after participating in their high intensity exercise training programme.

The results revealed that daily life was affected by the ability to make choices. Being informed about the cause of the chest pain and the positive aspects of being physically active seemed to impact on capability. Patients experienced their chest pain as giving them new

opportunities in living their daily life. This is in line with Nussbaum (1988), who talks about illness as a disruption in life. Some patients experienced chest pain as a causal link for giving up work. Participating in the exercise training programme broke the link, and some patients were able to work again as they did before the chest pain appeared (Study III). Patients stated that participating in the high intensity exercise programme helped them to find a balance between being guided by health staff and exercising autonomy. This is in line with Prah Ruger (2010), who claims that health capability offers promise in finding a balance by respecting the health consequences for each unique person and providing health agency.

Health capability was recognized as an improvement in health in terms of internal factors, such as experiencing being in a better mood, and external factors, such as feeling physically stronger in daily life (Study III). The results indicate that physical activity impacts on assessing an individual's level of health functioning, health agency and environment. Physical activity influences the ability to use the environment to act in a way that improves health (Study II, III). One interpretation is that the high intensity exercise seemed to help the participants to understand their own health capability. They reflected on their symptoms and their knowledge. Some talked about seeing more possibilities in life (Study III). However, the answers as to how they wanted be met are complex (Nussbaum 1988, Study I,II,III).

### **7.3 Development of patient capability**

To support patients' capability, a person-centered approach is suggested. There is no commonly agreed definition (Edvardsson, Winblad & Sandman, 2008) of person-centered care. Different approaches and labels are used, such as person-centeredness (Leplege et al., 2007), person-centred nursing (McCormack & McCance, 2006), person-centred caring (Edvardsson et al., 2008), client-centred care (Rogers, 1959) and patient-centred care (Mead & Bower, 2000; Stewart, 2001).

A person-centered approach means a shift from viewing patients as passive targets in care and treatment to including the patient and frequently people close to the patient, such as active partners (Ekman, 2014; McCormack & McCance, 2016). There is a relational ontology behind patient-centered care (Ekman et al., 2011), and this can encourage health professionals to look beyond task-oriented information. Viewing the patient as a person and person-centered health care has become a core competence for all health professionals (IOM, 2003; QSEN, 2005/2017). Ricoeur (Kristensson Uggla, 2011) highlights the receiver of care as a person with capabilities. He advocates this view to be laid down in societal institutions, such as the hospital context of the present thesis (Hetteema, 2014).

In a person-centered approach, the point of departure is taken from the patient's narrative, and includes a way of seeing the patient as an active partner. Ekman (2011) anchors the person-centered approach in what Ricoeur (1990) describes as an ethical perspective, where health professionals have an obligation to recognize and acknowledge the fragility of self and coherence in life.

According to Ekman et al. (2011) a person-centered approach emphasizes the importance of seeing the person as a worthy and capable person in a partnership with health professionals. Human resources and opportunities can be identified by listening to the patients' story. This can form the basis for a health plan as a partnership. The relationship between patient and health professional is underpinned by central values, such as mutual understanding and respect of the patient's self-esteem and will (Ekman, Norberg & Swedberg, 2014, p. 79). Returning to Studies II and III, this means, for example, considering the patients' experiences of being physical active when planning further activities.

Reciprocity is needed in the relationship. Within this lies a focus on the patient's individual problems and openness towards different ways of expressing questions. In addition, health professionals have to be aware

of the everyday language ambiguity in the patients' narratives. This points to the need for guidance and education in putting person-centered care into practice. The results of Study I give examples of patients not experiencing being seen as a person.

A systematic review (Resurreccion et al., 2019) has indicated that clinical factors (e.g. physical inactivity, poor functional capacity and lower exercise capacity), logistical factors (e.g. longer travel time, lack of transport and living in a rural area), and health system factors (such as lack of referral to cardiac rehabilitation, having a low level of endorsement from physicians) were the main factors assessed for not participating in cardiac rehabilitation. The participants in Study III of the present thesis were supported by the health professionals. All of them participated in the exercise training for twelve weeks, even if some, according to the interviews, were physically inactive, had poor functional capacity, and low exercise capacity before the training started. All of them managed to attend the training sessions and gave them priority. According to Ricoeur (Kristensson Ugglå, 2011, p. 279), the road is long for the "acting and suffering" man. The person has to recognize themselves as the person she or he really is; a person who is capable of different accomplishments.

One example of reducing uncertainty is, according to the results of Study I, the provision of information and being there for the patient. The patient is vulnerable in their uncertainty. In line with Ricoeur (1992), there is a balancing act in the patient's autonomy and vulnerability (Study II). This balancing act is one way of meeting uncertainty and vulnerability.

The results (Study III) show that both capability and vulnerability have to be taken into account in conversations and interactions. Ricoeur (Kristensson Ugglå, 2011) claims that seeing oneself as another is required for each step towards becoming more capable. Mutual recognition gives the patient and involved health professionals room for acknowledgement. Inherent to this is a statement of capability to

transition (Study III). The activities described in Study III with a room for training and supervision may have led to the patients recognizing a safe space for confronting the uncertainty of doing exercise training. At the same time, this was a familiar space for the health professionals to help the participants go further in confronting their uncertainty. It is necessary to present a clear description of the development process to participants (Study III). In addition, there is a need for support in explicating questions and beliefs (study III).

The participants experienced their capability as a practical opportunity. As described in Studies I and II, the health professionals recommended physical activities to the participants. When participating in the high intensity exercise programme, and thereby confronting their uncertainty, they also confronted or perhaps rather opened up to their own capability (Study III). Their achieved capability was experienced dynamically, shaped in the interaction between the patients, health professionals, the other patients participating in the training, as well as the environment (Study III). They felt safe in the environment with a defibrillator on the wall, a friendly atmosphere and highly qualified health professionals. The patients' references to a good life, where they could make rational choices, related to doing or avoiding physical activity (Study II).

*Discussion*

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## **8 Conclusion**

This thesis provides a patient perspective on everyday life for people in the context of living with unexplained chest pain. Hopefully, it contributes to deepening insights into the complexity of uncertainty. This thesis contributes with aspects and nuances related to what it means to live in a balancing act between existential uncertainty and certainty in connection with doing or avoiding physical activity, while living with unexplained chest pain. A person-centered approach meeting patients' beliefs, perceptions and verbal and nonverbal expressions of feelings related to experiencing unexplained chest pain should be added to existing models of consultations. Active patient participation, shared decision-making and a multidisciplinary approach aims to take patient experience into account.

To demonstrate an appropriate level of explanatory depth, the theoretical explanation of the transition process must include an underlying dimension on vulnerability. Central values as a basis for the relationship between patient and professional are mutual respect and understanding of the patient's self-esteem and will (Ekman et al., 2014 p. 79). This unique theoretical dimension may therefore provide significant additional insight into exercise training processes for people with unexplained chest pain. A person-centered approach is implied to encourage people to feel capable about creating rational choices related to doing or avoiding physical activity.

The individual manages and adapts to a multitude of changes giving rise to the chest pain and its treatment. Adapting to the exercise training has been conceptualized as an ongoing personal transition, one that has been illustrated as a process of becoming more capable. High intensity exercise training for people with unexplained chest pain includes a need for support from health professionals in explicating questions and

beliefs. It is suggested that substantive and formal theories that are relevant to practice and person-centered care be developed.

In all, this is about a shift in how healthcare views and considers the patient towards a person-centered approach. This thesis, based on the perspective of the patient, has highlighted challenges around unexplained chest pain as a “puzzling condition”. Hopefully, I have contributed with some pieces of the “puzzle”. As one participant (Study II) expressed it in the search for answers to her uncertainty: “You have to put the pieces of the puzzle together to start building a picture”.

### **8.1 Implications for practice**

The results of this thesis point to a number of relevant areas to consider in clinical practice with patients with unexplained chest pain.

Preconditions for person-centered practice/care as suggested are based in the results of the thesis:

- Teamwork among cardiologists, dieticians, specialized nurses, and physiotherapists, with genuine focus on the patient (seen as a person) perspective together with shared decision-making
- Educating health professionals in how to work in a person-centered way and continuous follow-up /participatory activities
- Knowledge of signs, symptoms and diagnosis
- Knowing what signs and symptoms mean for each person
- Knowledge of symptom expressions
- Knowledge of human science, complemented with a biomedical perspective
- Knowledge of high-intensity exercise programmes

- Important content in the conversation includes:
  - topics related to diet
  - physical activity
  - pain as a multifaceted phenomenon in life

## **8.2 Suggestions for further research**

This section presents suggestions for future research stemming from overall findings from this thesis.

- The thesis has especially shed light on information needs and physical activity for people with unexplained chest pain. Further studies are recommended to deepen our knowledge of other aspects/areas of living with unexplained chest pain. And there is also a need for effect studies of physical activity in relation to different variables, such as lifestyle factors, exercise and activity habits, inventory of pain, chest pain and daily activities, impact on daily life, health and wellbeing, pain belief and perception inventory, anxiety and depression.
- The overall aim of this thesis was to explore and describe experiences related to living with unexplained chest pain from the perspective of the patient. More research is recommended from the perspective of the health professionals as well. Health professionals need insight on the experiences of people with unexplained chest pain and guidance in interpreting bodily symptoms. Further studies are recommended where health professionals have time to reflect together with patients about living capable lives, and discuss using everyday language. More knowledge is needed about the impact of a person-centered approach from the health professionals' perspective.

Another recommendation for future research is to change and evaluate change in the organization of health care for people with unexplained

## *Conclusion*

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chest pain. This should be done on both a macro and a micro level in the organization. Effect studies are suggested that look at shared decision-making between the health professionals and the patient, as well as a multidisciplinary approach to gain an understanding of the patients. Finding out how often patients seek health care, how satisfied health professionals are with their work, and whether they find it meaningful, as well as considering the associated health care costs are all part of this approach.

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## **Appendices**

***Appendix 1 Paper I, Paper II, Paper III***

*Appendices*

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*Appendices*

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***Paper I***

*Appendices*

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## Exploring the information needs of patients with unexplained chest pain

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Ingrid Ølfarnes Roysland<sup>1</sup>  
Elin Dysvik<sup>1</sup>  
Bodil Furnes<sup>1</sup>  
Febe Friberg<sup>1,2</sup>

<sup>1</sup>Department of Health Studies, Faculty of Social Sciences, University of Stavanger, Stavanger, Norway; <sup>2</sup>Institute of Health and Care Sciences, Sahlgrenska Academy at Göteborg University, Göteborg, Sweden

**Background:** Unexplained chest pain is a common condition. Despite negative findings, a large number of these patients will continue to suffer from chest pain after being investigated at cardiac outpatient clinics. Unexplained chest pain covers many possible complaints, and diagnosing a single cause for a patient's pain is often described as difficult, as there are a number of possible factors that can contribute to the condition. For health professionals to meet patients' expectations, they must know more about the information needs of patients with unexplained chest pain. The aim of this study was to describe information needs among patients with unexplained chest pain and how those needs were met by health professionals during medical consultations.

**Methods:** A qualitative design was used. Data were collected by means of seven individual interviews with four women and three men, aged 21–62 years. The interviews were analyzed by qualitative content analysis.

**Results:** The results are described in two subthemes, ie, "experiencing lack of focus on individual problems" and "experiencing unanswered questions". These were further abstracted under the main theme "experiencing unmet information needs".

**Conclusion:** Existing models of consultations should be complemented to include a person-centered approach to meeting patients' beliefs, perceptions, and expressions of feelings related to experiencing unexplained chest pain. This is in line with a biopsychosocial model with active patient participation, shared decision-making, and a multidisciplinary approach. Such an approach is directly within the domain of nursing, and aims to take into account patient experience.

**Keywords:** information needs, qualitative research, unexplained chest pain

### Introduction

Many people will experience unexplained chest pain within their lifetime, although the majority will not have it investigated.<sup>1</sup> Bass and Mayou<sup>2</sup> claim that noncardiac chest pain is a common condition worldwide. Jonsbu et al<sup>3</sup> indicate that the majority of people referred to cardiac outpatient clinics for chest pain in Norway will be told that their pain is not due to a cardiac condition. Unexplained chest pain covers many possible complaints and diagnosing a single cause for a patient's pain is often difficult because there are a number of possible factors that can contribute to the condition.<sup>2</sup> Common causes are described as esophageal disorders, musculoskeletal problems, and pain referred from the thoracic spine, hyperventilation, and psychologic disorders. However, the risk of death from coronary heart disease is not significantly different to that in the general population,<sup>4</sup> but there is substantial morbidity attached to unexplained chest pain, with work absenteeism rates around 29%.<sup>5</sup>

Correspondence: Ingrid Ølfarnes Roysland  
Department of Health Studies, Faculty of Social Sciences, University of Stavanger, N-4036 Stavanger, Norway  
Tel: +47 5183 4133  
Fax: +47 5183 4150  
Email: ingrid.roysland@uis.no

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According to research,<sup>2</sup> people with unexplained chest pain are often more anxious, with a higher prevalence of panic disorder than people with heart disease, and a high percentage continue to take cardiac drugs.<sup>4</sup> Many have a similar level of functional disability and use health services as frequently as people with a positive diagnosis of heart disease. Persons with unexplained chest pain experience fear and anxiety, feelings of uncertainty, stress, and loss of strength.<sup>7</sup> Fagring et al<sup>1</sup> point to the fact that men and women had more similarities than variations in their descriptions of chest pain.

The traditional biomedical model has guided the assessment and treatment of persistent pain for many years.<sup>3</sup> As an extension of this understanding, the biopsychosocial model, including interaction of biological, psychologic, and social factors causing noncardiac chest pain and subsequent disability, is suggested.<sup>5,10</sup> According to this comprehensive model, all diseases have biopsychosocial components that contribute to the experience of unexplained chest pain and the response to treatment.

Thus, there are a variety of challenges related to the complexity of living with unexplained chest pain, which presumably indicates a need for more knowledge and understanding in order to handle everyday life. Information needs is defined by Knowles<sup>11</sup> as the gap existing between specific competencies and the ability of the learner to achieve these specific competencies at present. According to Timmins,<sup>12</sup> it is difficult to extrapolate from the literature an exact definition of information needs for acute coronary syndrome patients because no clear definitions or consensus upon terminology is found. There are few studies about information needs from the perspective of persons with unexplained chest pain. However, in a qualitative study, Price et al<sup>13</sup> aimed to understand the needs and experiences of attendees at a rapid access chest pain clinic and to determine the acceptability and effectiveness of the procedural changes. Changes in procedures helped patients to understand their pain, practice self-management, and consider altering their lifestyle. Another interesting aspect which points to the need to explicate knowledge needs further is the deviation between patients' actual needs and health care workers' expectations of those needs, as documented for coronary syndrome patients.<sup>12,14</sup> The studies indicate that participants focused on stress and symptom management rather than modifying health habits.

In order for health professionals to create person-centered communication to meet patients' expectations, there is a need to know more about the information needs of patients with unexplained chest pain. Person-centered communication seeks to elicit and satisfy the needs, preferences, and values

that patients express themselves.<sup>15</sup> Therefore, the aim of the present study was to explore information needs and how those needs were met by health professionals during medical consultations.

## Materials and methods

A qualitative design was used to gather indepth knowledge about experiences<sup>16</sup> related to the information needs of people living with unexplained chest pain.

## Participants

The participants were selected from a cardiac outpatient clinic at a university hospital in Norway. The inclusion criteria were diagnosis of unexplained chest pain (a cardiologist should have ascertained that patients' symptoms had no apparent organic cause), age at least 18 years, and ability to understand and speak Norwegian. All eligible participants had a symptom-limited bicycle test in the cardiac outpatient clinic, and were given information about their test results. They also received standard information about risk factors and lifestyle factors related to the development of heart disease. Exclusion criteria were the absence of chest pain symptoms and having pathologic cardiac findings after the bicycle test. Patients who met the inclusion criteria were consecutively invited to take part in the study via a letter distributed by the head nurse in the cardiac outpatient clinic. This consecutive selection continued for a 6-month period. Those who were interested in participating contacted the head nurse. Four women and three men agreed to participate. The men were aged between 58–62 years and the women were aged 21–60 years. Five participants had also been assessed for chest pain once or twice before, in this or another cardiac outpatient clinic, and were told that their chest pain was unexplained.

Two participants had an academic qualification, one was studying to obtain an academic qualification, and four had a vocational qualification. Three were working full-time, two were working half-time, and two were receiving disability compensation. Two of the participants' jobs involved physical work. Five participants lived in cities and two lived in rural areas.

## Ethical approval

The persons who agreed to participate received both verbal and written information about the study, and were assured that the data would be treated confidentially and that they were free to withdraw at any time. They were asked to sign a written informed consent at study entry. Approval was sought from the regional ethics committee (2009/2243-7),

and the investigation conformed to the principles outlined in the Declaration of Helsinki.

**Data collection**

Data were collected from semistructured individual interviews using an interview guide (Table 1). The interviews were narrative in form and were conducted as a conversation in which the informant was encouraged to talk freely.<sup>16</sup> The interviews were carried out by the first author under the same conditions in accordance with patient preference in an undisturbed room in either the cardiac outpatient clinic or in a room at the university. All interviews lasted for approximately one hour.

**Data analysis**

Interview texts were analyzed using qualitative content analysis, which included identifying meaning units, categories, subthemes, and theme,<sup>17</sup> to provide new knowledge and insights into the topic under investigation (Table 2). The analysis followed several distinct steps, from the interview situation to the validation of findings (Table 3): audiotaping and transcribing the interviews; reading the text several times; performing content analysis;<sup>17</sup> selecting quotes; and validation.

**Results**

A main theme of “experiencing unmet information needs” was formulated. This illustrates the latent content.<sup>17</sup> To retain the authenticity of the participants’ experiences, direct quotations from the interviews were selected to illustrate the most commonly reported aspects of each category or variation within the subthemes (Table 3). The two subthemes of “experiencing lack of focus on individual problems” and “experiencing unanswered questions” form the subheadings in the following presentation of results.

**Table 1** The interview guide

	Interview sequence with topics or questions asked
Opening	Interviewer introduction Information regarding the purpose of the interview
Main question	Can you tell me something about the information you received at the cardiac outpatient clinic?
Closing	Are there other important issues related to the information that we have not discussed, and that we should take into consideration when giving information to patients? Summary of main topics with the most important remarks

**Experiencing lack of focus on individual problems**

**Not being seen as a person**

The participants attended the cardiac outpatient clinic with uncertainties regarding their chest pain. They wondered how it would affect them in the future, and what treatment was needed. Most were positive towards the health professionals, but wanted them to focus on their individual problems. The majority of the participants perceived that the information was very general. One participant stated:

“[...] they don’t think that every person has individual questions and things they would like to know” (Woman, 21 years)

The bicycle test was perceived to be rather generic as well. They were not reassured by a negative result. The tests were not found to be tailored to them and their particular problems.

“That bicycle test for me is like, I did not get breathless or tired [...] I bike so much [usually] that I did not feel any of that [...] but they [the health professionals] are doing their program, even when they don’t get anything out of it. So to have gotten a result, I should have cycled properly.” (Man, 58 years)

Some indicated that they did not feel that the professionals listened to their individual history of pain. The participants regarded their perceived information needs as individual ones and expected the health professionals to look into their daily life. They wanted the physician to prescribe a more facilitating job situation, for example, including breaks, reduced working hours, and avoidance of night shift work with increasing age. One participant said she would have asked more questions if she felt there was room for this. The participants also said that they wanted to understand their chest pain. Some were confused after seeing the cardiologist and were no closer to understanding their problems after the consultation. However, one of the participants said the information was very useful.

**Lack of time for asking questions**

Some participants became confused because of the short consultation session.

“I didn’t [have time to] ask any questions or anything like that. They told me I could ask, but in a way, yes, it went like quick, quick, quick. So, it’s obvious, they do it [consultations] many times.” (Woman, 21 years)

**Table 2** Examples from the qualitative content analysis process showing abstraction from condensed meaning units, categories, subthemes, and theme

Condensed meaning unit	Category	Subtheme	Theme
They don't think of each person as having individual questions when giving information	Not being seen as a person	Experiencing lack of focus on individual problems	
The examination in the clinic which found unexplained chest pain, gave me many questions, but he (cardiologist) would not listen to my history			
Didn't have time to ask questions	Lack of time for asking questions		
They said you could ask, but there was no room for it			
People don't talk about it (unexplained chest pain)	Alone with the problems		Experiencing unmet information needs
Strange that they don't get (together) those who have the problems to talk with others			
No pattern for when getting pain, that is why I do not know what to ask about	Uncertain about how to formulate questions	Experiencing unanswered questions	
Not getting an answer why I feel this (chest pain)	Still uncertain of the cause of pain		
When cardiologist gives information, I do not ask			
Expect the doctors inform, based on their qualifications			
They found nothing wrong, but there is something, I feel pain			
Need an explanation, why I have chest pain			
When problems with the heart, it makes me frightened of exercise	Uncertain about how to exercise in a safe way		
The pain is so bad, I have to hold on to continue (exercising)			
The pain comes and goes (during exercise)			
The pain can come when I am eating	Uncertain if food is causing pain		
I don't know why the pain comes when I eat. It's a mystery			
Wondering about if special food is causing pain			
I am careful with what I am eating, because I am unsure about the connection to chest pain			

The participants felt unable to think things over and to ask appropriate questions within the time frame. Limited opportunities to discuss the diagnosis, particular worries, and further management were reported. One of the participants suggested that a website about chest pain should be set up so she could get more answers to her questions.

**Alone with their problems**

Most of the participants felt they were alone with their problems. Some felt that social contacts were difficult to maintain because the pain was bothering them so much.

"So often you just loaf about at home, you don't go out to a single thing, as crazy it may be. It's terribly wrong, I know myself. You have to pull yourself together, but it isn't always easy. It's not." (Woman, 55 years)

They also talked about the pain causing depression. One participant said:

"Because of that [the pain], I think it is very easy to get depressed, and it [the situation] feels as heavy as stones." (Man, 62 years)

The pain situation was a troublesome burden. This participant also blamed himself for the situation because he had

been working too hard for too long. He thought it would be easier to deal with if he had someone in the same situation with whom he could talk. Further investigation and referral to a cardiologist every second year were suggested as a follow-up preference by the participants. In such follow-up consultations, they could be investigated with the opportunity to share experiences of pain on a continuous basis.

**Experiencing unanswered questions**

**Uncertain about how to formulate questions**

The participants reported that it was difficult to ask questions when they did not know why they were in pain, and could not find any pattern to the level or intensity of the pain. They wanted the staff to inform them about what was important to know.

"Because I am of the opinion that when you come to a doctor, then he knows what to do [...] if he is good at informing, he just explains from the investigations." (Man, 56 years)

Several participants wanted the health professionals to inform them without first asking questions. Due to difficulties in formulating their questions, the participants wanted the professionals to be alert to both verbal and nonverbal

**Table 3** Stages of the qualitative content analysis

1	The interviews were taped and transcribed word for word.
2	The transcribed interviews were carefully read through as a whole several times to gain a contextual understanding of the patients' information needs. Important nuances were discovered by searching for common distinctive features, as well as variations.
3	Patterns in the data were identified by dividing into meaning units (eg, constellation of statements that relate to the same central meaning).
4	The meaning units were condensed, with the core preserved.
5	Categories were created as groups of expressed manifest content with shared commonality, and subcategories (eg, sentences to be sorted and abstracted into a category).
6	Subthemes and a main theme; the meaningful essences that run through the data were constructed and based on manifest and latent content.
7	Selection of quotes. There was agreement regarding which quotes were to be selected to illustrate each category.
8	Validation of findings. The counsellors agreed with and acknowledged the relevance of the findings after each interview. They also highlighted other areas of importance that were included.

indicators of information needs. They wanted the health professionals to impart information using appropriate everyday words so that they could understand what had been communicated.

**Still uncertain of the cause of pain**

The participants' most frequently mentioned need was to know what was causing the chest pain, and all of them considered this to be important. All but one of the participants thought they had a cardiac disease, even though their cardiologist told them that the test results were negative.

"The physician said he could not find anything wrong with my heart, but there is something. There is something, because I feel it." (Woman, 58 years)

The participants still felt the same chest pain as before the consultation, and were not reassured about the result of the test.

"But I have something, somewhere in the cardiovascular system. I have no doubt." (Man, 58 years)

There were no connections found. The participants did not find a pattern for their chest pain, which made them uncertain. They wanted to understand their chest pain, why it fluctuated over time, and why it changed without understandable

reasons. The participants wanted to be able to help themselves and to know what to do.

"The only thing I missed [during the consultation in the cardiac outpatient clinic] was basically, what is it [the chest pain], and what can I do about it?" (Woman, 21 years)

Participants reflected over possible causes. Most of them had someone in the family with heart disease and wondered if their condition was related to heredity. They reflected on what information their family members had received regarding the cause of their pain, and wondered if their own chest pain was caused by the same thing. Others wondered if there could be psychologic causes. Even if they did not have problems like anxiety or depression, some participants reflected over possible psychologic causes. Causes in daily life were also reflected upon, such as various stressful events and burdens.

**Uncertain about how to exercise in a safe way**

Physical activity was emphasized by all participants. Advice on an adequate level of activity was of interest, as was advice on how to respond when the pain starts.

"I can sit normally, like I do now, and then lifting 100 kilograms here, and then down to the floor, quite a number times. So I think I can use my chest and all this here then. And then, there is no pain at all, there isn't. I wonder if I have been using my muscles incorrectly, even though I don't think so." (Man, 60 years)

According to this participant, the pain comes and goes and is not associated with exercise. Some participants were confused by being told to exercise in spite of pain and expressed anxiety about doing exercise. Some admitted lack of physical strength and/or self-confidence in performing common daily activities. The physician in the cardiac outpatient clinic told the patients that they had less chance of developing heart disease if they were in good shape. Even well trained participants said that they had intensified their training after being told in the cardiac outpatient clinic that physical training can help them to avoid chest pain. Only one of the participants had limited exercise after the consultation and was striving to "get started".

**Uncertain if food is causing pain**

Some of the participants wondered if their diet was causing chest pain, but could not find a connection.

"But on the other hand, you can only think: why do some get pain, and then I think; they can't find anything [cause of the chest pain]. So I'm not so sure of anything. But then

I have to add: I'm not the world's cleverest man when it comes to food, I must admit. So I could certainly have been more careful with my diet. I could certainly have been more careful about many things, and maybe it has something to do with that, I don't know" (Man, 58 years)

Symptoms of heart burn were experienced. Four participants had been referred to gastroenterologists to look for esophageal sources of their pain. Two of them had gastroesophageal abnormalities. At that time, it was indicated that this could be the cause of the chest pain. The participants nevertheless wondered what in their diet could give chest pain.

"But I know at least that when I eat, it [chest pain] can come [...] I've felt it with egg sometimes, but I don't know why. But it can be other things as well [...] like bread, so it's a mystery" (Woman, 54 years)

Some were careful about what they ate, and suggested that more information be given about ways of improving their health by dietary changes.

## Discussion

The aim of this study was to explore the information needs of people with unexplained chest pain and how those needs were met by health professionals during medical consultations. The participants experienced that their information needs were not adequately met. The two subthemes of "experiencing lack of focus on individual problems" and "experiencing unanswered questions" form the subheadings in the following discussion.

### Experiencing lack of focus on individual problems

The results of our study indicate that patients felt that they did not receive attention for individual problems when attending the cardiac outpatient clinic. This is supported by Price et al<sup>13</sup> who pointed out that patients wanted a definite diagnosis, an understanding of the problem, and to learn about self-management. Laburnée et al<sup>18</sup> argue that there are no standardized rules and methods to deliver information and education or to evaluate the results of therapeutic education. This clearly points to the responsibility of health professionals to identify patients' information needs. In our study, all participants had received general information about their condition and risk factors for developing a cardiac condition. Timmins<sup>12</sup> found in her study that a natural conflict existed between nurse and patient priority of information needs among acute

coronary syndrome patients. According to Timmins,<sup>12</sup> there is agreement that cardiac patients should have individualized teaching based on assessment of information needs, but there is no clear explanation of precisely what this is. This is in line with our findings, which indicate a conflict of needs priorities in terms of what health professionals and patients value as important information. Presumably, this may influence the level of uncertainty, as described in the study.

In health care, the traditional biomedical model often guides assessment and information in connection with medical consultations.<sup>19</sup> One main focus is to evaluate whether there is a physical condition present that may explain the symptoms. It is important to diagnose and treat pathologic pain conditions, because a diagnosis will indicate or guide treatment options. All participants in our study said that their chest pain was influenced by their own experiences and was unique to them. This is also in accordance with the biopsychosocial model<sup>2,10</sup> which contributes to understanding of psychosomatic and environmental components in unexplained chest pain.

Participants expressed that it was not easy for them to communicate with anyone about problems related to their chest pain. Some also expressed anxiety and depression. Van Ravensteijn et al<sup>20</sup> point out that diagnostic testing hardly impacts on the level of someone's doubts and fears. Jerlock et al<sup>7</sup> suggest nurses could talk to patients to elicit their illness narratives in order to have a deeper understanding of the patients' experiences. This was also shown in our study. In a study by Price et al,<sup>13</sup> communication problems were identified and interpreted as related to failure of clinical procedures to meet patients' needs. According to Dammen et al<sup>8</sup> and Jonsbu et al,<sup>3</sup> psychologic factors may play a role in the pathogenesis of unexplained chest pain. It is indicated that there is a higher proportion of panic disorder and major depressive episodes among this group of patients. Depression and poor social support are significant risk factors for coronary heart disease<sup>21</sup> and panic disorder,<sup>22</sup> while stress and anxiety can trigger coronary events.<sup>22</sup> It is also claimed that people experiencing such psychosocial difficulties are more likely to be physically inactive, which is also an independent risk factor for cardiac heart disease. Robertson et al<sup>23</sup> reported that people with unexplained chest pain viewed their conditions as significantly less controllable and less understandable than those whose pain was cardiac in origin. As suggested by Robertson et al,<sup>23</sup> a multidisciplinary approach to meet patients' different information needs is required. In addition, a sympathetic appreciation by the health professionals to take psychologic factors into account in the communication

with the patients is suggested. Such approaches presumably promote active patient participation. They may reduce psychologic and psychosocial difficulties and help the patients to experience more control and understanding, and as such reduce cardiac risk factors.

### Experiencing unanswered questions

The participants were uncertain about how to formulate questions and did not feel their questions were answered. In the cardiac outpatient clinic, they were informed that the results of the tests were negative but remained uncertain about the cause of the pain. The participants were uncertain about how to exercise in a safe way and about issues related to their diet. A definition of uncertainty, which is valid across disciplines, is proposed by Penrod,<sup>24</sup> who indicates that people who are uncertain have a perception of being unable to assign possibilities for what to do or think. This was also true of the participants in our study, who felt pain but had no explanation for it. According to Penrod,<sup>24</sup> this promotes a discomforting, uneasy sensation that may be affected through cognitive, emotive, or behavioral reactions, or by the time and changes in perception of circumstances.

The participants in our study had received information that a pathologic cardiac condition did not explain their chest pain, resulting in their uncertainty. However, their experience of chest pain may have forced them to search for alternative explanations which link chest pain with heart disease. Following Leventhal et al.,<sup>25</sup> the chest pain compels the individual to create a subjective perception of a heart disease, which subsequently inspires a search for specific bodily signs of cardiac pathology. These researchers point to the importance of modeling patients' subjective perceptions of the investigation, procedures they use to manage their problems, questions they ask, and the criteria they use to evaluate outcomes. According to research,<sup>25-28</sup> it is increasingly important to understand how the perceptions, experiences, and impact of having pain might influence a person's interpretation and response, so that health professionals can, in turn, respond more appropriately. This is in line with person-centered care,<sup>13</sup> which is focused on the patients' narrative, partnership, and documentation of negotiated care and decisions.

The majority of the participants in our study were not reassured by the information that heart disease was not the cause of their chest pain. Some of the participants described the pain as "mysterious". If the person's pain beliefs are ignored, it may complicate or entirely undermine the reassurance of having negative findings of heart disease. This is in accordance

with reports by several other authors,<sup>29-31</sup> who found that if pain becomes persistent, patients may abandon previously held cultural or personal beliefs about pain to form new pain beliefs that are more consistent with their persistent pain experience. Preparing patients by means of information for negative test results is assumed and may make it easier for them to accept simple reassurance from a cardiologist or cardiac nurse.<sup>31</sup>

According to the results, the participants were uncertain about how to exercise in a safe way. Thompson et al.<sup>15</sup> claim that important information for the participants must focus on the positive results of physical activity and that immobility might be far more harmful for them. A study by Williams et al.<sup>14</sup> indicates that patients' perceptions of their own risks are often not a reflection of their true risks. The patients in their study overestimated their risk factors compared with an objective measure, regardless of whether they received information or not. In relation to our study, the participants did not receive explanations of cardiac origin for their chest pain. They were still uncertain about how to exercise in a safe way and expressed anxiety about doing physical exercise.

Some of the participants in our study expressed a lack of physical strength for daily living. Wise and Patrick<sup>32</sup> stress that a modest increase in daily activities can improve health and quality of life for persons with unexplained chest pain. Jonsbu et al.<sup>16</sup> use the expression "noncardiac chest pain". In their study, patients with noncardiac chest pain were exposed to physical activity as a part of a cognitive behavioral therapy intervention. According to Mayou,<sup>19</sup> patients with noncardiac chest pain may have high levels of fear of body sensations, and it is assumed that a reduction of this fear will lead to a decrease in patient limitations, for example, with exercising. In the study by Jonsbu et al.,<sup>16</sup> it was therefore assumed that exposure to physical activity could be a useful element. When exposed to physical activity, the treatment group in their study showed significantly larger improvements in terms of reduced avoidance of physical activity, fear of bodily sensations, depression, and some domains of health-related quality of life. Some participants in our study expressed avoidance of physical activity and fear of physical activity because of the chest pain they felt.

Our participants also reported problems with digestion. Hershcovici et al.<sup>17</sup> claim that gastroesophageal reflux disease (GORD) is by far the most common cause of noncardiac chest pain. Further, they say that esophageal dysmotility is relatively uncommon among patients with non-GORD-related noncardiac chest pain. They argue that it is still unclear if longitudinal esophageal muscle contractions are a direct

cause of chest pain or if they represent an epiphenomenon that is associated with symptoms of such pain.

Some of the participants experienced anxiety and depression. Lillestøl et al<sup>10</sup> claim that anxiety and depression are common in patients with self-reported food hypersensitivity. However, according to Lind et al,<sup>16</sup> psychologic factors were not major predictors of symptom severity in patients with subjective food hypersensitivity. The participants in our study had chest pain and no cause of cardiac origin was found. They still believed they had a heart disease, but also considered other explanations for their chest pain. Notably, some were investigated for GORD.

### Implications for practice

The results indicate that listening to patients' beliefs, perceptions, and expression of feelings related to experiencing unexplained chest pain should be encouraged and acknowledged by health professionals. The patient's narrative is thus a useful tool in the consultation when dealing with the complexity of living with information needs and uncertainty related to unexplained chest pain. Topics related to physical activity and diet seem to be important content in conversation. Dialoguing about pain as a normal and multifaceted phenomenon in life is also suggested as important. A multidisciplinary approach, such as team work among cardiologists, dieticians, specialized nurses, and physiotherapists, with a genuine focus on the patient perspective, and on shared decision-making is proposed.

### Methodologic considerations

Because few individuals agreed to participate, we acknowledge that some data may be missing. However, the material gives important answers to the research questions and discloses both manifest and latent content. Although age and gender varied in the sample, the data analysis revealed only minor variations. To secure trustworthiness, several aspects, including credibility and dependability, were evaluated. Credibility was secured by ensuring that issues related to the selection<sup>16</sup> of the most suitable meaning units, and how well categories and themes covered the data, were critically discussed by all authors. The interviews were audiotaped and transcribed verbatim. Both factors of instability and the risk of inconsistency during the data collection procedures were discussed by all coauthors. The transferability of our findings can be considered by taking into account the description of participant context, data collection, and process of analysis.<sup>17</sup> To strengthen the credibility of the analysis, categories, subthemes, and

theme in the search for manifest and latent content were identified and formulated in the course of the research team's discussion.

### Conclusion

This study reveals unmet information needs, specifically a lack of focus on individual problems and unanswered questions during medical consultations as experienced by people with unexplained chest pain. Existing models of consultations should be complemented to include a person-centered approach meeting patients' beliefs, perceptions, and expression of feelings related to experiencing unexplained chest pain. This is in line with a biopsychosocial model with active patient participation, shared decision-making, and a multidisciplinary approach. Such an approach is directly within the domain of nursing, and aims to take into account the patient's experience of their condition.

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### Disclosure

The authors report no conflicts of interest in this work.

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## Appendices

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Information needs of patients with unexplained chest pain

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*Appendices*

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***Paper II***

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*Appendices*

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***Paper III***

*Appendices*

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ORIGINAL ARTICLE

## Confronting one's vulnerability – patients with chest pain participating in a high-intensity exercise programme

Ingrid Ølfarnes Røysland, Febe Friberg, Berit Store Brinchmann, Sunniva Nordeide Svello, Torstein Valborgland and Alf Inge Larsen

**Aims and objectives.** To explain the transitional process that individuals with unexplained chest pain undergo while participating in an exercise training programme over time.

**Background.** Angina-like chest pain in patients with no obstructive coronary artery disease is a growing problem. Functional limitations, restricted daily activities and reduced quality of life are reported. In addition, physical activity is avoided in this population.

**Design.** The study follows a qualitative classic grounded theory (Glaser 1978).

**Methods.** Three times a week for 12 weeks, twelve patients with no obstructive coronary artery disease participated in a high-intensity aerobic exercise training programme supervised by physiotherapists and nurses. The data collection was based on diaries and interviews about the experience and analysed according to the principles of classic grounded theory.

**Results.** The core category was identified as 'confronting one's vulnerability' and included three subcategories: 'balancing existential uncertainty', 'transforming bodily perceptions' and 'becoming a more capable person'.

**Conclusion.** The transition was described as a process of becoming more capable. Health professionals should be aware of the significance of high-intensity exercise training for people with unexplained chest pain and of the underlying dimension of vulnerability.

**Relevance to clinical practice.** Understanding the transition process that people with unexplained chest pain undergo while participating in a high-intensity exercise training programme promotes a person-centred approach. Taking this substantive theory into consideration will improve the prerequisites for establishing person-centred care.

**Key words:** exercise/physical activity, experiences, grounded theory, heart-health, pain, uncertainty

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**Authors:** *Ingrid Ølfarnes Røysland*, MSc, RPN, Doctoral Student, Department of Health Studies, Faculty of Social Sciences, University of Stavanger; *Febe Friberg*, PhD, RN, Professor, Department of Health Studies, Faculty of Social Sciences at the University of Stavanger, Stavanger; *Berit Store Brinchmann*, PhD, RN, Professor, Nord University Bodo, Norway and Nordland Regional Hospital Trust, Bodo; *Sunniva Nordeide Svello*, MD, Doctor of Medicine, Department of cardiology, Stavanger University hospital, Stavanger; *Torstein Valborgland*, MD, Doctor of Medicine, Department of

cardiology, Stavanger University Hospital and Department of Clinical Sciences, University of Bergen, Bergen; *Alf Inge Larsen*, MD, PhD, Professor, Department of cardiology, Stavanger University hospital and Department of clinical sciences, University of Bergen, Norway

**Correspondence:** Febe Friberg, Professor, Department of Health Studies, Faculty of Social Sciences, University of Stavanger, N-4036 Stavanger, Norway. Telephone: 0047 51834251. E-mail: febe.friberg@uis.no

### What does this article contribute to the wider global clinical community?

- It increases understanding of the transition process that patients with unexplained chest pain undergo while participating in a high-intensity exercise training programme.
- Nurses and other health professionals may use the insight gained from this study to develop new person-centred approaches to high-intensity exercise training to support patients' capability building.
- The grounded theory appears to be transferable to patients with unexplained chest pain in countries other than Norway.

## Introduction

Unexplained angina pectoris-like chest pain in patients with no obstructive coronary artery disease (CAD) is a growing clinical problem (Eslick 2007) where angina symptoms persist and even worsen over time, restricting daily activities (Lanza & Crea 2010). Residual morbidity is indicated, which is associated with functional limitation and reduced quality of life (Kaski *et al.* 2013).

After the exclusion of other cardiac diseases and in the absence of obstructive CAD, the diagnosis of microvascular angina is often suggested (Lanza & Crea 2013). This is often characterised as cardiac syndrome X (CSX) and is defined as typical chest pain associated with electrocardiographic changes suggestive of transient myocardial ischaemia despite normal coronary angiograms (Patel *et al.* 2010). Microvascular coronary dysfunction, such as reduced coronary microvascular dilatatory responses and/or increased coronary microvascular resistance or microvascular spasm, has consistently been reported in CSX patients (Lanza & Crea 2013). Because of fear of precipitating angina as well as increased pain sensitivity, many patients with persistent chest pain are often afraid to exercise (Kaski *et al.* 2013). This uncertainty may lead to avoidance of physical activity (Jerlock *et al.* 2006, Jonsbu *et al.* 2010). According to Amundsen *et al.* (2007), reduced physical activity is one of the major avoidance behaviours in patients with coronary heart disease.

## Background

Physical activity is here defined as 'any bodily movement produced by skeletal muscles that result in energy expenditure' (Caspersen *et al.* 1985, p. 126). Further, exercise is a subset of physical activity and is defined as 'structured and repetitive and has final or intermediate objective as improvement of, or maintenance of physical fitness' (Caspersen *et al.* 1985, p. 126). It has been shown (Eriksson *et al.* 2000, Tyni-Lenne *et al.* 2002, Feizi *et al.* 2012) that patients with CSX demonstrate increased exercise capacity and quality of life after participating in cardiac rehabilitation programmes comprising physical training in combination with relaxation in comparison with those in control groups who did not. Therefore, it can be assumed that a variety of different forms of training can contribute to the improvement of everyday life for this group of patients. Simultaneously, there seem to be unanswered questions about unexplained chest pain and physical activity (Author 2013), specifically, how to formulate questions, uncertainty about the cause of the pain, how to exercise in a safe way and uncertainty whether food caused the pain.

The above arguments suggest that there is a gap between what is recommended in terms of exercise training and what patients with unexplained chest pain choose to access. It is essential to reduce this discrepancy. More specifically, there is a need to know more about the process of training from the patients' perspectives. A substantive theory grounded in experiences in a context-specific personal transition process may have considerable potential for giving us a more complete understanding of the transition process.

Thus, classic grounded theory (Glaser & Strauss 1967, Glaser 1978) was here used to reveal the transition process. The focus was placed on the basic psychosocial process of the transition. The aim of the study was to explain the transitional process that individuals with unexplained chest pain undergo while participating in an exercise training programme over time.

## Methods

### The study

This study was part of a larger project where the main objectives were to assess the effect of high-intensity aerobic exercise training on coronary flow reserve (CFR), endothelial function, exercise capacity, level angina and psychological function in individuals with chest pain and no obstructive CAD. The CFR is thus the limiting factor for myocardial perfusion when there is no coronary epicardial disease. An improvement in CFR associated with improved exercise capacity and reduction in chest pain is thus the main objectives in the main pilot trial.

### The study setting

The study was a single-centre interventional controlled pilot trial performed at Stavanger University Hospital, Stavanger, Norway. Two specialised physiotherapists and three experienced research nurses led the exercise training, during which popular music was played. Physicians who were part of the team were always available. The participants exercised on treadmills in groups: two groups with four participants and two groups with two participants.

The exercise training sessions lasted 38 minutes and consisted of a 10-minute warm-up period at moderate intensities [60–70% of maximum heart rate (HR) based on the results of an initial exercise test], followed by a total of four intervals at 90–95% HR<sub>max</sub> (85–90% VO<sub>2</sub> peak) with 3 minutes of active recovery phases at 60–70% HR<sub>max</sub> in between intervals and at the end of the session. See Fig. 1 for details about the exercise training programme.

## Appendices

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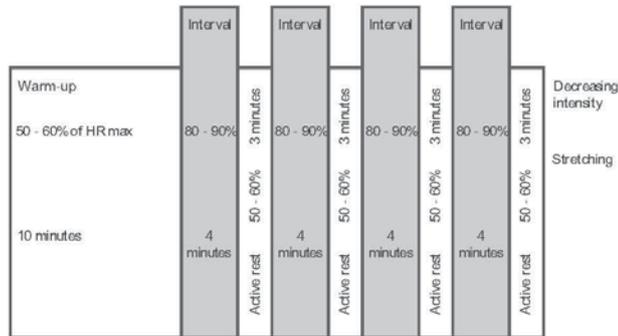


Figure 1 High-intensity aerobic exercise training programme, HR<sub>max</sub> = maximum heart rate. Frequency and duration: three times per week for 12 weeks. Time: Monday, Wednesday and Friday at 7:30 am or 14:30 pm.

Patients exercised three times weekly over a 12-week period. The intervention took place at the outpatient cardiac rehabilitation centre at Stavanger University Hospital.

The training sessions were monitored with individual HR monitors (Polar RS100; Polar electro, Kempele, Finland) for intensity guidance. This enabled the patients to achieve their target HR and to assess the actual level on the Borg scale of perceived exertion coinciding with the target HR. Instructors continuously reminded the participants to monitor intensity levels by viewing the HR monitor. Next to each screen was a figure resembling Fig. 1.

### Recruitment and sample

Patients with typical exercise-induced chest pain and normal or near-normal coronary arteries assessed by coronary angiography were contacted by a cardiologist and invited to an information meeting where they were briefly oriented about the project and given the opportunity to ask questions. Interested patients were asked to write their names on a list and were contacted again by the cardiologist or another physician in the team. A sample of twelve participants agreed to participate in the exercise training programme (Table 1). Demographical data are presented in Table 2.

### Ethical approval

Ethical approval was obtained from the regional ethical committee (2013/98). The investigation conformed to the principles outlined in the Declaration of Helsinki. All participants provided informed consent prior to their inclusion in the study. Confidentiality and anonymity were safeguarded according to ethical research guidelines.

### Data collection and analysis

Before starting the exercise training, several tests were performed: CFR, echocardiography, flow-dependent vasodilatation, blood tests and 24-hour heart rhythm monitoring. A maximal stress test on treadmill was performed to assess electrocardiography (ECG) changes, angina, blood pressure and arrhythmia at baseline and at 12-week follow-up. During this test also, ergo spirometry was performed. Unstable patients with pathological blood pressure or arrhythmias during the test would be excluded. The detailed description and results from the physiological tests will be presented in another article.

The data analysed and presented in the current article consisted of diaries with reflective comments and individual

Table 1 Criteria for participating

Inclusion criteria	
Outpatients and patients admitted to the hospital with repeated	episodes of exercise-induced chest pain
Normal or near-normal coronary angiogram or negative	computerised tomography (CT) coronary angiogram
Age >18 years	
Being able to participate in training groups three times a week	
Exclusion criteria	
Prior myocardial infarction	
Serious valve disease	
Cancer	
Previous radiation or drug therapy for cancer	
Musculoskeletal problems making exercise training impossible	
Ongoing serious inflammatory disease	
Intracardiac devices	
Presumed insufficient acoustic windows for transthoracic	echocardiography
Atrial fibrillation	
Participation in other ongoing studies.	
Contrast allergy	
Contraindication to adenosine infusion	
Vasospastic angina	

Table 2 Characteristics of participants

Characteristics	
Gender	
Female	7
Male	5
Age	
40–45	1
46–50	1
51–55	–
56–60	2
61–65	3
66–70	4
71–75	1
Marital status	
Married	10
Divorced	1
Cohabitant	1
Children	
1–2	7
3–4	5
Educational attainment	
Vocational certificate	8
College/university up to four years	2
College/university more than four years	2
Employment condition	
Working full time	4
Working part time	1
Sick leave	2
Disability pension	2 (1 part time because of an injury)
Retirement pension	4
Chest pain for:	
4–6 months	1
7–12 months	1
1–2 years	2
2–4 years	5
4–6 years	3
Smoking – daily	1
Drinking alcohol – daily	–

interviews. In the diaries, the participants were asked to reflect on the following questions, one, two and three months after starting the training. The questions were as follows:

- Please describe how you have been affected by chest pain in the past month.
- Please describe how your chest pain has affected your daily life in the past month.
- Please tell us what the physical activity group you are participating in has meant to you over the past month.

Participants kept diaries that were delivered to the nurse administrating the tests and the exercise training groups after one, two and three months. The interviews were based

on the diaries and carried out after the exercise programme was finished. Interviews were tape-recorded and transcribed verbatim. Data collection took place from November 2013 June 2014. We were inspired by Glaser and Strauss' constant comparative method (Glaser & Straus 1967, Glaser 1978) when identifying the basic social and/or psychological process that takes place when exercise training, thereby understanding the complexity of what is going on. Grounded theory is based on a symbolic interactional view of human behaviour. It provides a systematic way of generating theoretical constructs and concepts that illuminate human behaviour (Glaser & Straus 1967).

In line with classic grounded theory method (Glaser & Straus 1967, Glaser 1978), data collection and analysis occurred simultaneously, as the ongoing analysis of the reflective diaries steered further data collection through individual interviews. According to Glaser (1978), entire incidents rather than fragments of the data must be considered in the analysis. The analysis included open coding, selective coding, memo-writing, theoretical coding and sampling. During the comparative analysis, each level of coding moved the analysis towards increasing levels of abstraction. The analysis was validated by comparing data on the different levels of abstraction. The developing pattern of the grounded theory was thereby read in relation to all data to ensure validity. The analysis in progress was discussed within the researcher group. The reflective diaries were analysed in tandem with the individual interviews. In this way, the reflections were read and the interviews were listened to several times to discover a variety of perspectives. Selective coding was performed by transferring a limited selection of codes over to larger parts of the collected data. All the codes were then compared with each other. In the theory under development, the core category 'confronting one's vulnerability' was identified.

## Results

### Confronting one's vulnerability

The participants' main concern was uncertainty about exercise training. They were uncertain about their bodily reactions and the risk of worsening their heart problems while training. As chest pain was experienced by the participants to be a possible indication of heart disease, it contributes to the constitution of vulnerability. The core category explains the personal transition process that the individual undergoes while participating in the programme of physical exercise, with the help of the subcategories: 'balancing existential uncertainty', 'transforming bodily perception' and 'becoming a more capable person'.

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### Balancing existential uncertainty

Agreeing to participate in the project was the beginning of a personal transition process. Many of the participants expressed uncertainty about physical activity before being tested and before the exercise training started. Doing physical activity is an indicator of the basic social psychological process of keeping going in the context of daily life, despite the state of uncertainty represented by symptoms that may be a sign of heart disease. An existential dimension exists here in that participants talked about exercise bringing them into the vicinity of illness and even death. One participant expressed it as 'the Dahle Oen effect'. Dahle Oen (1985–2012) was World champion, European champion and Norway's first Olympic medallist in swimming. He died suddenly of a heart attack in 2012. Being uncertain made the participants vulnerable. Embarking on an exercise training programme seemed to imply a process in which existential uncertainty was challenged. Against the background of not knowing enough about the erratic pain in their chests, the participants wondered what kind of exercise they could do, how far they could walk and how much they could carry, for example, when shopping.

The participants drew on or had been exposed to various experiences throughout life. Some had always exercised or even had a vocational connection with physical exercise. Others had led sedentary lifestyles, but most were somewhere in between. In addition, participants had different experiences of illness and heart disease among friends and family. The different sources of experiences could often be seen as being linked to participants' more immediate perceptual or emotional responses. Examples included experiences of anxiety, reassurance or a sense of acceptance.

Being asked to participate was seen as a chance to break the vicious circle of effort-induced chest pain, functional limitation and uncertainty. Being contacted by the professor or a physician from the hospital and asked to participate in this project was described as 'a gift from above' or 'getting a second chance in life'. Participants talked about 'being selected', 'being privileged' and 'being prioritised'. They all wanted to participate.

### Transforming bodily perceptions

Nearly, all the participants were positive about doing all the medical tests taken before starting the exercise training. For them, the tests represented high-quality health care, which could provide answers about their heart and the functioning of the heart and the body. They were of the opinion that the health staff working on the project were

among the best in the country in this field. The staff were perceived as friendly, skilled, experienced and knowledgeable. The fact that the intervention procedures were well planned (no waiting time) was experienced as positive, which was also commented on as evidence of the quality of the intervention. One participant expressed it in this way: 'You notice that people are professionals. It's the way they are. They know what they are doing, and you see it straight away'. Another pointed to the safe environment: 'I said to my husband that I could not be more secure with a heart starter on the wall'. Being embraced by such a secure environment seemed to encourage bravery in facing the limits of physical effort and even fatigue. At the same time, bodily and cognitive attention was directed towards a possible pain in the chest. All these paved the way for reconsidering old ways of thinking about chest pain.

Differing strategies were adopted in the personal transition process. The participants watched the screen on the treadmill to observe changes in their HR. They followed the measurements on the screen and the physical reactions caused by the exercise training. Some participants tried to understand the relationship between what they were watching and what they were experiencing in the body during the warm-up, the intervals with maximum HR and active rest. They compared what they saw on the screen with what they were experiencing in the body. The invisible became visible, thus increasing the possibility to make reflective considerations.

Some participants stated that their way of thinking changed from being uncertain about and afraid of high-intensity exercise to being reassured by it and that they even experienced exercise as beneficial. Increased HR, breathlessness and chest pain made them anxious and uncertain before participating in the project. But now, this was seen as safe and a way to feel better and stronger. Most of the participants experienced an increase in chest pain at the beginning of the exercise training period. This could have been challenging, but they saw the exercise as being completely safe.

After a while, the participants felt their physical fitness increase. One strategy was to warm up before doing the hard exercise and slowdown at the end. Most of the participants shared experiences with other participants, and they encouraged others to continue. The groups were, for most of the participants, of great value, although nobody expected the relationships to last for more than these three months. Some also talked about exerting themselves in daily life when participating in the project. They were testing their limits. Participants who had previously experienced extra-systoles said there had been less of this after participating in the training programme. This kind of

exercising was described as being essential for living a good life. Some had reorganised their work day and daily life to exercise three times a week. Several of the participants also reported that they slept better. All the participants did what they could to follow and complete the whole programme, and all were successful in completing it. One informant summarised it in this way: 'It's not my body holding me back anymore. It's as if I'm the one in control over my body, in a way. And it's very nice! So I feel it has been a very good experience'.

#### Becoming a more capable person

Experience of participating in the exercise training programme enabled participants to become more capable. Through participation, these individuals were brought into an experience of distressing uncertainty, but they moved on to the process of alleviating distress by letting go and being reassured. The participants experienced confidence in physical activity despite their chest pain. They moved from uncertainty about physical activity and chest pain to experiencing physical activity as something that gave them strength. The participants focused on making sense of recent events. They reflected over their experiences of symptoms and their knowledge of the body and mind. Most of the participants expressed feeling much better and talked about seeing more possibilities in life. One participant, for example, wanted to go back to work after having been on sick leave and disability benefits for two years.

Becoming more capable created possibilities. Most participants felt better than they expected after taking part in the exercise training programme. They experienced personal growth and gained an enhanced outlook on life. One expressed it as 'coming out of the quagmire'. Another patient said:

'I am also a bit uplifted because I have experienced fewer symptoms of ... as I think ... activity in the heart region or ... I cannot define it ... but that thing (heart pain authors' comment). I have not experienced/sensed it so much now when I train. So I believe that ... I think it (the training, authors' comment) has managed somehow to get these symptoms away in one way or another'

Even participants who exercised regularly before participating in the programme expressed a difference in fitness and mood. Their explanation for this was the kind of exercise they did in the project (see Fig. 1). One said: 'Exercising is good, both for the heart and the head'.

The participants planned to continue exercising as they had been taught because of the difference in mood and fitness the training had made. In addition to feeling stronger

and fitter, the following consequences were described by the participants: increased enjoyment in life, improved sleep, feeling calmer. They expressed awareness of valuable functioning. Increased capability also enabled the participants to relate to the professionals in a different way than before. They experienced being seen by the health staff as whole persons and collaborative partners.

The participants had less or no chest pain after participating in the programme. Several also said that being part of the project had reassured them about heart disease and chest pain. For some participants, the project represented 'something else' as they struggled in their daily lives. They looked forward to connecting in a friendly atmosphere, to having good relationships with the health professionals and the other participants, and also the exercise. This was described as giving them strength and lighting up their daily lives. One participant summarised it this way:

'I'll give you an idea. Yes, that [participating in the project] has had a very positive influence on me. So, yes, I feel very good. And then I'm working, I'm always working on getting a better life, so it's basically a journey all the way

The personal process by which the individuals adjust while participating in the programme of physical exercise is illustrated in Fig. 2.

#### Discussion

The participants' main concern was uncertainty about their bodily reactions and the risk of worsening their heart problems while exercising. In this study, we found that confronting one's vulnerability is the core category that explains the personal transition process in terms of 'balancing existential uncertainty', 'transforming bodily perceptions' and 'becoming a more capable person'.

The results indicate that most of the participants were uncertain about living with unexplained chest pain, but that they also had to deal with existential challenges. In Bredal's study (2012), experiences of participating in physical activity when living with a disability were explored. Results from her study suggest that physical activity may have an existential meaning and might influence the way participants experience their own body and abilities. This is in line with Roysland and Friberg 2016, who found that being physically active while living with unexplained chest pain means finding a balance between existential uncertainty and existential certainty. Most of the participants in this study described uncertainty related to physical activity before embarking on the project and exercising.

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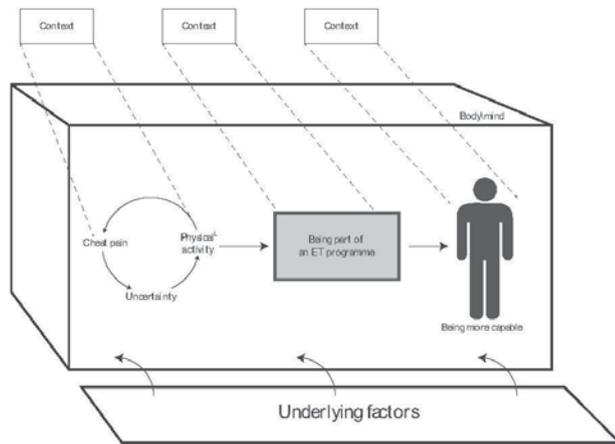


Figure 2 Participating in the exercise training (ET) programme.

All the participants saw taking part in the study as a way of getting answers to individual questions about the meaning of their chest pain. According to Roysland *et al.* (2013), participants with unexplained chest pain experienced a lack of focus on their individual problems during medical consultations. Participants in the current study did physical exercise on a treadmill in a setting where well-educated and experienced health professionals were open to conversation. The participants valued being tested, as well as the possibility of getting a diagnosis, and they talked about being 'seen' and 'selected' when they were asked to participate in the project, which implied testing and training.

In a review, Van Ravensteijn *et al.* (2012) studied the efficacy of using diagnostic tests to reassure patients. The results indicate that the diagnostic tests contribute little to the level of reassurance. Most of the participants in our study had been tested before and no indication of heart disease had been found, despite the chest pain. After being tested this time, they were told their chest pain was probably caused by microvascular dysfunction. Having been informed of the cause of their chest pain, the participants were reassured that the high-intensity exercise included in this intervention would be beneficial for them. The patients included in this study had chest pain that we suspected might be microvascular angina. It is possible that these particular patients will experience better effects from physical exercise training than other chest pain patients because the exercise can improve microvascular flow and thus reduce symptoms.

Several of the participants described having chest pain as a 'crisis'. According to Kleinman (2011), understanding life as a perception, illness as a symbol, or medicine as a cultural form is not what matters at times of crises. Rather, it is the subjective experience of individuals, their sensibilities, commitments, values and experience of will as authorising feelings. Our study reflects this in the way the participants expressed a sense of vulnerability, and how the chest pain affected the life they valued as worth living. This is a hallmark of person-centred care, in which listening to the patients' narrative and trying to understand how, for example, pain influences their daily life, dignity and capability are emphasised (Ekman *et al.* 2011).

All the participants had experiences earlier in life, which can be assumed to have influenced the transition process. These did not specifically concern physical activity but also experiences of the healthcare system. Some talked about challenging nonmutual encounters where dignity was violated. According to Jacobson (2009), any human interaction can be a dignity encounter, an interaction in which dignity comes to the fore and is either violated or promoted. At the intra- and interpersonal levels, service users and practitioners might reflect on their own positions of vulnerability and antipathy and on the nature of their gestures; what they say and do. In this study, experiences of previous encounters with health professionals were interpreted as influencing the transition process.

According to the participants in our study, acquiring chest pain might mean struggling to adjust to a new and

changed life situation. It is not the body seen solely as an object that needs to be rehabilitated. Neither can it only be seen as a different or changed body that one has to adjust to emotionally. The participants who go through a transition process do not simply have a body; they are their bodies (Merleau-Ponty 2002). Merleau-Ponty (2002) claims that there is an interconnectedness between body and the world when he argues that it is the body that actively anchors us in the world (p. 408). The participants said that after the exercise training programme, their bodies were stronger and faster and no longer restricted them. This is in line with other studies (Eriksson *et al.* 2000, Tyni-Lenne *et al.* 2002, Asbury & Collins 2005, Samim *et al.* 2010, Feizi *et al.* 2012).

Twelve weeks of exercise training resulted in a change in the capability participants experienced. Jarvis (2006) argues that there may be benefits acquired from physical activity, which also incorporate a mental dimension. This affects the way the body operates in the world. As the participants express it, there are benefits from the exercise training for both the mind and body. Parallels can be drawn to Morken *et al.* (2012) who argue that participating in an exercise training programme increases confidence to engage in physical exertion and increases satisfaction with life for other groups of coronary heart disease patients, such as implantable cardioverter defibrillator recipients. The importance of an integrated approach is stressed. Ruger (2010) argues that current theoretical approaches to bioethics and public health ethics propose varied explanatory justification as the basis for healthcare and public health. Yet, none captures a fundamental reality: people seek good health and the ability to pursue it.

Most of the participants in our study suggest that the intervention programme needs to be a part of the regular treatment of patients with unexplained chest pain. Some argue that this could save the healthcare system large amounts of money. In line with Nussbaum (1988), it is emphasised that health political policies must support such arrangements. Getting chest pain can be an unexpected disruption and can break the causal link between good arrangement and good functioning. The findings in this study indicate that participants want the health professionals to enable them to achieve individual targets for their health. Ruger (2010) defines health agency as individuals' ability to achieve health goals they value and to act as agents of their own health. Health functioning is the outcome of the action to maintain or improve health. The participants valued taking part in the intervention programme and expressed this as being of great importance for their further functioning in life.

### Limitations

Conducting any research that involves individuals reporting on their own experience also involves the possibility that they will respond in a socially desirable manner. However, grounded theory encourages us to examine and question participants' responses to elicit rich and full data (Glaser 1978). The exploratory in-depth nature of classic grounded theory should therefore facilitate the retrieval of an accurate representation of respondent experiences. Another aspect is that all participants declared their interest in taken part in the study. Thus, possible consequences of the self-selection could be positive participants from the beginning. This has to be considered in future research. All 12 interviews were conducted just after finishing the exercise training and before taking the tests to ensure that the test results did not affect what was said in the interviews. Only those who were able to participate in training groups three times a week participated in the study. This recruitment strategy may have biased the findings, as the participants lived within a restricted geographical area. However, participants came from both cities and rural areas. Further research with other populations will help clarify and refine this initial classification of the transition process of people with unexplained chest pain.

Due to the above limitations, the information presented here is not regarded as the only explanation or the complete explanation for the transition process. However, the findings may have theoretical and clinical relevance. The professionals have to be aware of how complex it is for the participants to change their ways of thinking and acting as a result of a transition. Both capability and vulnerability have to be taken into account in conversations and interactions. In the research team, we have been aware that it is necessary to present a transparent account of the development process to participants.

### Conclusion

In summary, we argue that theoretical explanations of the transition process must include an underlying dimension on vulnerability, to demonstrate an appropriate level of explanatory depth. The confronting vulnerability concepts identified in this study therefore represent a unique theoretical dimension, which may provide significant additional insight into exercise training processes for people with unexplained chest pain. Adapting to the exercise training has been conceptualised as an ongoing personal transition as the individual manages and adapts to a multitude of changes precipitated by the chest pain and its treatment.

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Transition has been described as a process of being more capable. Health professionals should be aware of the significance of high-intensity exercise training for people with unexplained chest pain. This includes the need for support in explicating questions and beliefs. Further, substantive and formal theories that are applicable to practice and relevant to person-centred care should be developed.

### Relevance to clinical practice

Physical activity is recommended for people with, as well without, CHD. An implication for practice in this study is that 'confronting vulnerability' has significance in the context of participating in an exercise training programme. It is crucial to consider a perspective that starts from each person's experience (Liden *et al.* 2015). This must nevertheless be complemented with the biomedical perspective (Brink & Skott 2013). A substantial theory of the transition process for patients going through a high-intensity exercise training programme promotes a person-centred approach where patients' perspectives are included. Taking this substantive theory into consideration will improve the prerequisites for establishing person-centred care.

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### Contributions

Study design: IR, FF, BSB, AIL, TV, SNS. Data Collection and analysis: IR, FF, BSB. Manuscript preparation: IR, FF, BSB, AIL.

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### Conflict of interest

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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## Appendices

Original article

Chest pain

- patients with unexplained chest pain. *BioMed Central Nursing* 5, 7. (an open access journal).
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***Appendix 2 Ethical approvals***

*Appendices*

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***Ethical approvals***

*Appendices*

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## Appendices

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Fra: Regional komite for medisinsk og helsefaglig forskningsetikk REK nord

Til:  
Terje A. Murberg  
terje.a.murberg@uis.no

Dokumentreferanse: 2009/2243-7  
Dokumentdato: 01.02.2010

FREMME TILTAK FOR BEDRE REHABILITERING FOR PASIENTER MED BRYSTSMERTER UTEN KARDIOLOGISKE ÅRSAKER. - INFORMASJON OM VEDTAK

Vi viser til prosjektleders tilbakemelding av 18.01.2010 med vedlegg.

Etter fullmakt er det fattet slikt

**vedtak:**

*Prosjektet godkjennes.*

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK. Vi gjør oppmerksom på at hvis endringene er "vesentlige", må prosjektleder sende ny søknad, eller REK kan pålegge at det sendes ny søknad.

Det forutsettes at forskningsdata oppbevares forskriftsmessig.

Godkjenningen gjelder til 31.12.2013

Prosjektleder skal sende sluttmelding i henhold til helseforskningsloven § 12.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. forvaltningsloven § 28 flg. Eventuell klage sendes til REK Nord. Klagefristen er tre uker fra mottak av dette brevet.

Vennlig hilsen  
May Britt Rossvoll  
Sekretariatsleder

Beate Solbakken  
Førstekonsulent

Regional komité for medisinsk og helsefaglig forskningsetikk, Nord-Norge  
REK NORD

Besøksadresse: TANN-bygget, Universitetet i Tromsø, N-9037 Tromsø  
telefon sentralbord 77 64 40 00 telefon ekspedisjon 77620758 e-post: post@helseforskning.etikkom.no

## Appendices



Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	04.03.2013	2013/08/REK_vest
			Deres dato:	
			22.01.2013	
			Vår referanse må oppgis ved alle henvendelser	

Alf Inge Larsen  
Hjerteavdelingen  
Stavanger universitetssykehus

### 2013/98 Har høyintensitetstrening effekt på koronar flow-reserve, endotelial dysfunksjon og psykologiske aspekter hos pasienter med brystmerter og normale koronararterier?

**Forskningsansvarlig:** Helse Stavanger HF  
**Prosjektleder:** Alf Inge Larsen

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 14.02.2013. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikklovens § 4.

#### Prosjektomtale

Pasienter med brystmerter og normale koronarårer har i dag ikke et veletablert behandlingstilbud. Disse pasientene plages ofte av tilbakevendende brystmerter, og mange har forandringer i de minste hjerteårene, som medfører forstyrret evne til å regulere blodgjennomstrømmingen. Hensikten med studien er å kartlegge hjerteårenes evne til å øke blodgjennomstrømming. Hypotesen er at et etablert treningsopplegg kan forbedre hjerteårenes funksjon som igjen vil kunne føre til mindre brystmerter. Man vil også kartlegge hvilken effekt treningen har på psykiske aspekter hos pasientene. Pasientene inndeles tilfeldig i to grupper der en av gruppene deltar i et treningsprogram og den andre gruppen ikke deltar i programmet, men har samme oppfølging. Treningen vil foregå tre ganger i uken i tre måneder. I tillegg blir det gjennomført blodprovetaking, ultralyd av hjerte, ultralyd av pulsåre på armen, 24-timers hjerterytmeregistrering, myokardscintigrafi (undersøkelse for å måle blodstrømmen gjennom hjertet), MR av hjernen og besvarelse av sporreskjema. Det innhentes også opplysninger fra pasientjournalen. Man tar sikte på å inkludere ca. 200 pasienter til denne samtykkebaserte studien.

#### Vurdering

##### Informasjonsskriv

Prosjektet er omfattende og ambisiøst. Komiteen har ingen innvendinger til prosjektets plan for gjennomføring. Informasjonsskrivet må imidlertid merkes med logoen til den forskningsansvarlige (Helse Stavanger HF) og REK-nr. 2013/98. Det må fremgå av skrevet at pasientene er forsikret i studien gjennom pasientskadeerstatningsordningen og deltakerne må informeres om når prosjektet avsluttes og opplysningene slettes. Deltakerne må videre informeres om mulige risiko, ubehag eller ulemper ved deltakelse i studien. Begrepet «myokardscintigrafi» må forklares, og skrivefeil og ordelingsfeil i forespørselstittelen må rettes. Informasjonsskrivet må revideres og sendes til REK Vest. Skjemaet «Tilbakemelding» kan sendes uavhengig av fristene.

Besøksadresse:  
Haukeland  
Universitetssykehus,  
Sentralblokken, 2. etg, Rom  
4617

Telefon: 55975000  
E-post: rek-vest@uhb.no  
Web: <http://helseforskning.etikk.com.no/>

All post og e-post som inngår i  
saksbehandlingen, bes adressert til REK  
vest og ikke til enkelte personer

Kindly address all mail and e-mails to  
the Regional Ethics Committee, REK  
vest, not to individual staff

## Appendices

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### *Biobank*

Det legges opp til å måle betennelsesmarkører i blodprøvene. For lagring av prøvene søkes det om å opprette en ny spesifikk forskningsbiobank med tittelen «Sindex». Komiteen godkjenner forskningsbiobanken der ansvarshavende er Alf Inge Larsen.

### **Vilkår**

Informasjonsskrivet må revideres og sendes til REK Vest.

### **Vedtak**

- 1. REK Vest godkjenner prosjektet på betingelse av at overnevnte vilkår tas til følge.*
- 2. REK Vest godkjenner opprettelse av forskningsbiobanken Sindex i samsvar med forelagt søknad. Som ansvarshavende godkjennes professor Alf Inge Larsen.*

### *Sluttmelding og søknad om prosjektendring*

Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 31.10.2016, jf. hfl.

12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

### *Klageadgang*

Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Jon Lekven  
komiteleder

Camilla Gjerstad  
rådgiver

### **Kopi til:**

[forskning@sus.no](mailto:forskning@sus.no)  
[biobankregisteret@fhi.no](mailto:biobankregisteret@fhi.no)

*Appendices*

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***Appendix 3 Interview guide study I, II***

*Appendices*

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***Interview guide study I, II***

*Appendices*

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Intervjuguide. Fokusgruppe. ”Fremme tiltak for bedre rehabilitering for pasienter med brystmerter uten kardiologiske årsaker.” Murberg, Dysvik, Røysland, 04.09.2009

## INTERVJUGUIDE

### I Nåværende situasjon

- Kan du fortelle hvordan det er å leve med brystmerter?
- Hvordan opplevde du utredningen ved kardiologisk poliklinikk?
- Kan du si noe om informasjonen du fikk ved poliklinikken?
- Fortell om hvordan det har gått med deg etter at du ble utredet ved kardiologisk poliklinikk?

### II Smerteopplevelse

- Hvordan opplever du smertene dine?
- Kan du si noe om når smertene utløses, forverres eller plager deg mest?

### III Mestring av situasjonen

- Kan du si noe om hva som hjelper deg å få en redusert smerteopplevelse?
- Kan du si noe om hva du selv kan gjøre for å lindre smertene, evt. unngå at smertene oppstår?
- Dersom du skulle velge, hvilke oppfølging ville du foretrekke framover?

## OPPSUMMERING

Er der andre viktige problem relatert til å leve med brystmerter som vi ikke har diskutert og som vi skulle tatt i betraktning når tilbud til pasienter utvikles?

Oppsummering av hovedtemaene med de viktigste kommentarene.