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## Women with coronary heart disease – making sense of their symptoms and their experiences from interacting with their general practitioners

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### ABSTRACT

Cardiovascular disease and particularly coronary heart disease (CHD) is the leading cause of death among women and men worldwide. CHD in women, and their symptoms and treatment trajectory are not well understood. Studies indicate gender-related differences in symptom presentation, comorbidity, help-seeking behavior, and the quality of diagnostics and treatment of CHD. Although the incidence rates among men have decreased over the last decades, myocardial infarction among women has been increasing. Studies suggest limited knowledge among patients and doctors about the nature of CHD symptoms in women. Knowledge of patients' experiences and descriptions of symptoms may have important impact on diagnostic decision-making. This qualitative interview study explored how female patients experienced and understood their CHD symptoms and the treatment provided by their general practitioners (GPs). Nine patients scheduled for coronary artery bypass graft surgery were recruited from the waiting list, and interviewed before surgery. Data were analyzed by drawing on phenomenological method. The women reported various symptoms, including atypical symptoms such as fatigue, back and shoulder pain and dyspnea. The CHD symptoms were sometimes masked, and interpreted as gastro-esophageal reflux, chronic obstructive pulmonary disorder, asthma, nervous problems and muscular pain. While some accepted their doctors' diagnoses, others perceived their symptoms as due to tiredness, burnout and increasing age. Delayed treatment and misdiagnosis were explained by factors including failing to seek help and misinterpreting symptoms. There was a widespread frustration with doctors' ignorance of symptom descriptions, diagnostics and treatment approach. Women and their GPs may experience difficulties in recognizing CHD symptoms, resulting in misdiagnosis and inadequate and/or delayed treatment. The quality of the patient-provider communication is vital in preventing these problems. More knowledge and awareness about women's CHD is needed – both among health providers and in public.

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## 1. Introduction

Cardiovascular disease is the leading cause of death among women and men worldwide (Townsend, Nichols, Scarborough, & Rayner, 2015). Although coronary heart disease (CHD) in men has declined, the incidence of myocardial infarction (MI) among women aged 35–79 has increased over the last decades (Mannsverk et al., 2012). In addition, women experience their first acute MI on average 9 years later than men (Anand et al., 2008), with poorer outcomes and enhanced risk of death and re-infarction (Graham, 2016). Besides, women with positive ischemic tests are less likely than men to be diagnosed with CHD prior to their MI (McSweeney, Lefler, & Crowder, 2005), and less likely to receive coronary interventions (Worrall-Carter, McEvedy, Wilson, & Rahman, 2016) or optimal CHD treatment, and particularly when treated by male physicians (Baumhäkel, Müller, & Böhm, 2009).

These differences may reflect general gender inequalities in health and health care (Denton, Prus, & Walters, 2004). However, the fact that women with CHD tend to report “vague” symptoms such as fatigue, dyspnea, indigestion, and diffuse back pain, diverging from the more distinct male symptoms pattern with pinching chest pain radiating to the left arm (Coventry, Finn, & Bremner, 2011), may challenge the clinical decision-making and probably contributes significantly to these differences (Welch, Lutfey, Gerstenberger, & Grace, 2012).

In northern Norway, a relatively high prevalence of CHD (Forsdahl, 2002) has led to an increased emphasis on diagnostic and preventive measures of CHD (Mannsverk et al., 2012). Since the Norwegian public healthcare system strongly relies on primary health care for the initial diagnostics, treatment as well as referrals to and follow-ups after treatment in the specialized health services, the diagnostics and doctor–patient communication in primary health care are crucial.

The aim of the present study was to acquire new knowledge about how women with CHD experience and interpret their symptoms and their communication with their general practitioners (GPs).

## 2. Method

### 2.1. The study hospital

The Department of Thoracic and Vascular Surgery at the University Hospital of North Norway treats approximately 2000 inpatients annually (2011), including 340 coronary artery bypass graft (CABG) surgery patients.

### 2.2. The participants

A convenient sample of female patients with a CHD verified by coronary angiography was recruited from the waiting list for first-time CABG surgery. Patients with serious comorbidity were excluded. The nine participating women were ethnic Norwegians ranging from 47 to 78 years (see Table 1). Patients were recruited by mail or at arrival at the hospital. After returning a signed consent form, the interviewer contacted them and made an appointment for the interview.

**Table 1.** The patients.

	Age	Symptoms	CHD trajectory	Comorbidity and risk factors	Patient's attribution of symptoms	Doctor's diagnosis
Torill	53	Shortness of breath, chest pain	9 months since first symptoms	COPD, family with CHD, mother CHD at 40, brother at 39	Asthma, COPD, food intolerance, gastric reflux,	CHD
Eva	48	Fatigue, back-pain, shortness of breath, chest pain, radiating to arm and jaw	MI at age 36, PCI procedure at 39	CHD in family, hypercholesterolemia	Age-related, heart problem	CHD, confirmed by angiography last month
Berit	50	Back pain, shortness of breath, fatigue	2 years since first symptoms	Diabetes, family with CHD	Expressed worries for CHD	Muscle pain, conclusion no CHD symptoms
Anne	74	Stomach, chest-pain, jaw and nose, fatigue	10 years with angina	Hypertension, hypercholesterolemia, peripheral arterial disease, abdominal aortic aneurism, pyelitis	Pyelitis, CHD	CHD
Siw	70	Stomach and shoulder pain, reduced general condition, shivering	5 years since first symptoms, waited 1 year before consulting GP	Hypertension, family with CHD	Stress, workload	GP provided sick-leave, no info about diagnosis
Hansine	78	Chest pain	A prior MI not previously identified	Chest injury, diabetes, hypercholesterolemia last 40 years	Bruised rib	Bruised rib, nerves, psychosomatic
Sara	74	Chest pressure, palpitations, back pain	First symptoms 8 years ago, CHD diagnosis last month	High BP, gallstones, sphincter muscle	Gastric reflux, sphincter muscle, back pain	CHD but ECG negative, gastric reflux, sphincter muscle
Janne	47	Chest pain, radiation in arms, shortness of breath	3 years symptom, CHD diagnosis 2 years, MI 2 years ago not identified	Hypercholesterolemia, strong heredity for CHD in family, well known by GP	Gastric reflux, first MI perceived as reflux	CHD but ECG negative, gastric reflux → surgery, COPD
Liv	70	Chest pain, radiation in arm	Angina 12 years ago	Heredity for CHD	Heart problem	CHD

### 2.3. The interviews

The interviews were conducted at the hospital by the first author (a fourth-year medical student) 1–7 days prior to elective surgery, and were approximately one hour in length. Analyses were based on text transcriptions of the audio-recorded interviews.

A qualitative interview approach was applied, following Kvale and Brinkmann (2009), with open-ended questions, encouraging rich descriptions of personal experience and understanding of symptoms and the diagnosis-making process. The interviews were guided by the following questions:

How did you experience the early signs and symptoms of the illness? What were your own thoughts about these symptoms prior to consulting your GP? What was the GP's response and interpretation of your symptoms and complaints? What types of diagnostic or treatment have been provided? How was the course of your illness until today? How did you experience the treatment you have received?

Follow-up questions were used to clarify and get more details.

## 2.4. The analysis

The analyses followed the phenomenological method as described by Giorgi (1997) and Kvale and Brinkmann (2009). The approach followed five steps: (1) a word-by-word transcription of the interviews, (2) detailed reading and subsequent discussion regarding the content, (3) breaking-up of the data into units of meaning, (4) reorganizing the data, drawing on categories of meaning emerging of the data and (5) the synthesis of the data through the writing process. The three authors collaborated on all steps of the analysis. After nine patients, the inclusion of new patients was stopped due to data saturation (no more categories appeared).

## 2.5. Ethics

All patients signed a written consent form, and permissions were obtained from the Regional Medical Ethics Committee. Names and identifiable information are changed to protect the identity of the participants.

## 3. Results

Three main categories with respective sub-categories emerged from the analyses: “Masked diagnosis”, “Typical symptoms identified as CHD” and “Dissatisfied with the GP”.

### 3.1. Masked diagnosis

#### 3.1.1. Atypical symptoms

Several of the women had felt some unpleasantness in their chest, although not perceived as “real pain”. Torill (53) described it like this:

I've not had that typical pain in the chest, and not in the arms, maybe a kind of tearing feeling, but it didn't make me scared. This stinging is a little unpleasant, it doesn't really hurt, but it restrains me from doing my daily duties.

Back pain was a recurring symptom. The months prior to the infarction Eva (48) was worried:

I wondered if there could be something wrong with my heart or my lungs, because I often felt pain in my back.

Fatigue and tiredness were frequent. Eva (48) explained:

I felt terribly tired when I came home from work. I had no energy, nothing more to give. I couldn't get up from the chair after dinner, couldn't do anything. I thought something must be wrong. When I was out walking; it felt as if I didn't have enough oxygen.

Shortness of breath was Berit's (50) initial complaints:

I was short-winded and had a little pain in my back.

Torill (53) had chronic obstructive pulmonary disorder (COPD) and her shortness of breath became worse:

I walked up a hill. When I came to my house I couldn't manage to walk from the hall to the living room, and I had to sit down on a chair. This differed from earlier, the extent of short-windedness.

Anne (74) described other symptoms:

I was sort of tired. I have felt chest pain, a kind of tightening in my chest, and my waist felt narrow. I can't wear anything tight; often I need to keep my sweater away from my stomach. And it has radiated up to my nose, I feel it there!

Siw's (70) first symptoms appeared five years ago while she was working in a shop:

I felt so bad that I had to go to the storage room, to calm down. I couldn't handle that people were talking to me. It started with this shivering in my diaphragm, propagating to the whole body. I was really shaky. It didn't hurt. It just was so unpleasant. If I have felt pain, it is behind the right shoulder.

### *3.1.2. The women's own explanations*

Twelve years after the first infarction, Eva (48) started to feel in bad shape:

I thought that I was tired, maybe because I had worked too much. I'm not 20 years old anymore. You have to realize that stepping down is necessary; at the age of 50 a person doesn't cope with as much as at the age of 20.

Siw (70) gave a similar explanation to her symptoms:

I just assumed that I had got enough of everything, of work, of stress and rush.

Some attributed the symptoms to existing non-cardiac health problems. Torill (53) had her asthma/COPD for 20 years. She perceived the CHD symptoms as asthma-related:

Every time I felt pain in my chest I assumed it was my lung bubbles exploding.

Symptoms were also perceived as food allergy and reflux of gastric acid. Torill (53) had these thoughts:

I thought I reacted to some food, such as onion, which I quitted to eat. In February I was on a hike and my chest was hurting while ascending a hill. It was an awful pain. But my only thought was about the food!

After hurting her chest in a fall, Hansine (78) had heavy chest pain the following five weeks. She did not fully recover, and was referred to hospital. Their conclusion was MI, and they even found traces of a prior MI. Convinced that her chest pain was caused by the fall, she had delayed consulting her GP:

I had pain in my chest. Didn't think it was something with the heart. I assumed that I was bruised, that it was the ribs. I've broken 3 ribs earlier and it took several weeks to heal.

### *3.1.3. Receiving a non-cardiac diagnosis*

Sara (74) reported chest pressure and palpitations but the results of the angiographic examination were negative. Her GP's conclusion was a gastric reflux diagnosis. She did not agree:

I haven't thought of other explanations myself. My doctor told me that there was something wrong with my sphincter muscle between the ventricle and oesophagus. I wasn't encouraged to think of the heart. I was encouraged to think of my stomach.

Janne (47) had familial hypercholesterolemia, and consulted her GP with chest pain radiating to the arms. However, the GP found no indication of CHD, and concluded with gastric reflux:

It was the stomach. When the doctor tells me that the pain is caused by the gastric acid, I believe him. I'm not a doctor, so I don't know.

She had surgery for her reflux problems, but the chest pain remained. Her doctor diagnosed it as COPD. Janne (47) continued:

The doctor told me that I had COPD. But I thought it was something strange with this diagnosis making. I didn't feel like having COPD. COPD doesn't hurt!

Others were diagnosed with muscle pain. Berit (50) repeatedly consulted her GP for her back pain, shortness of breath, tiredness, and a pressure in her chest:

The doctor explained that it had to be muscular because women may have it that way. The pressure in my chest was due to muscular pain.

Hansine (78) consulted her doctor a few days after her fall with chest pain, and he explained that she was bruised. At the next visit, he suggested that her pain was psychosomatic:

He gave me Sobril (Oksazepam, a benzodiazepine derivate) for the pain. It was caused by nerves, he meant.

#### **3.1.4. Examinations revealing a prior MI**

Hansine (78) had at least two non-cardiac diagnoses prior to the referral to hospital and the surprising message:

There, they told me that I had a prior MI and that this was the second one.

Janne (47) got a similar message, and she remembered an event that may have been the infarction two years ago:

I was waiting for surgery of my stomach and was sure that this caused my pain. I had an awful pain – and it was provoked by stress. When driving my car, I had to stop, but it didn't improve! I vomited, but I knew I had too much gastric acid. It was the stomach. My doctor had ruled out a heart disease. I had been examined. I relied on it! But if I hadn't got a reflux diagnosis, I guess I would have called for health care when having this attack.

### **3.2. Typical symptoms identified as CHD**

Liv (70) had her first angina 12 years ago:

It felt like a claw in my chest, and it radiated to the arm. I knew it was the heart from the very beginning. We have heredity for heart disease (in my family). I went to the doctor's office immediately.



Eva (48) had an MI 12 years ago and also had typical symptoms that could easily be interpreted as signs of heart disease:

I was so sure, that the pain came from the heart. It started where the heart lies, and went upwards. I've heard about this radiation to the jaw and the arms, so I had no doubt. I remember the feeling like someone took a grasp in my left arm, pulling it off.

### 3.3. Dissatisfied with the GP

#### 3.3.1. Superficial understanding and treatment approach

Hansine (78) had, according to her GP, nerve problems and received benzodiazepine medication. She disagreed and was angry:

He'll get them back the next time I see him. I mean – I'm a balanced person. Nerves – no! I'm not scared. I don't have any problems! I guess prescribing pills is the easiest way to go nowadays. Almost like giving candy to the kids to make them quiet.

She continued:

My GP, I don't think he takes me seriously! When he's sitting there staring at his computer and not looking at you!

Berit (50) had similar experiences. The GP's conclusion was a muscular pain diagnosis, and gave the following explanation:

Muscular problems are common in women because of our diverse activities; we are working, carrying kids and so on. And we have a lot of fear and anxiety.

The doctor told her that her symptoms were not the symptoms of CHD:

I expressed my worries for having a CHD, and that I had a family history where both my mom and dad had a sick heart. But he meant that you don't get the symptoms that I had.

Berit (50), who was diagnosed with diabetes, was strongly advised to physical exercise. However, the CHD, that had recently been recognized, made physical exercising too difficult. She experienced a lack of understanding from her doctor on these issues:

It was important to think about life style and that my level of physical activity was too low, they said. But, I had to explain; I couldn't cope with such activities. I felt weary for anything. (But they didn't understand). They just said that I had to develop this capacity. But when I felt lack of this capacity, you know, I tried, but I couldn't get it anyway".

Janne (47), who was diagnosed with reflux and COPD prior to her cardiac diagnose, experienced a similar lack of understanding from her GP:

He told me it was COPD, but I couldn't rely confidently on that explanation. I consulted him again, and once more he explained COPD to me. I tried to explain to him that I didn't get any better after the surgery for the reflux problem, and that I still had pain! And when I returned, telling him that the COPD medicine didn't work, he only suggested trying another type.

When symptoms were typical for CHD, treatment satisfaction tended to be high, as exemplified by Liv (70). She had typical symptoms and immediately thought of a heart disease:

I got help when I asked for it, can't expect more than that. One need to say the word, we know how our symptoms feel like. There was no hesitation because I had a detailed description.



### 3.3.2. Frustrated by the incorrect diagnosis

Those experiencing long periods of misinterpreted symptoms and misleading diagnoses were frustrated. Janne (47) described typical symptoms but a cardiac diagnosis was ruled out due to the negative ECG and ultrasound examinations. After a long disease trajectory, she finally had an angiographic examination, confirming sclerotic coronary arteries:

I reacted negatively when my GP told me that I had COPD. He didn't consider heart disease at all! He knows my family history. (...) He wouldn't hear anything more about a possible CHD after the negative results of the ECG and the ultrasound examination.

Berit (50) had well-known risk factors including diabetes, CHD heredity and hypercholesterolemia, but presented more atypical symptoms. She expressed frustration about the incorrect diagnosis:

I've been irritated, because, why didn't the doctors think about this earlier when I had this kind of clinical picture and a strong family history. Maybe this could have been avoided, my disease recognized earlier, and only one artery would have been narrowed. Blocking of that artery could have been sufficient.

## 4. Discussion

The women reported atypical symptoms such as fatigue, back- and shoulder pain, shortness of breath, pressure and pain in the upper gastric area and even over the nose, and chest sensations not characterized as pain. Other studies have reported additional symptoms such as throat pain, neck pain, jaw pain, mid-back pain, nausea, vomiting and palpitations (Coventry et al., 2011; McSweeney et al., 2005).

Our findings indicate that non-cardiac diagnoses such as gastro-esophageal reflux, COPD, asthma, fatigue, muscular pain and nervous problems may mask or disguise the CHD. Disguising diagnoses may also include anxiety, depression, indigestion, hiatus hernia, arthritis, sciatica, temporomandibular joint pain, mitral valve prolapse, gallbladder disease, and diabetes (McSweeney et al., 2005). The relatively higher frequency of atypical, non-chest pain symptoms (Canto et al., 2012) and comorbidity (Worrall-Carter et al., 2016) among women versus men seem to be a trap in the diagnostics of women with CHD (Ricci, Cenko, Varotti, Puddu, & Manfrini, 2016). The resulting diagnostic uncertainty may reduce the likelihood that the physician order tests or treatment appropriate for an urgent cardiac condition (Welch et al., 2012), and increase the risk of being misdiagnosed and receiving delayed or not optimal treatment (Graham, 2016). Comorbidity and atypical symptoms (non-chest pain) are often co-occurring, and patients with one or both of these are less likely to receive evidence-based medical treatment or invasive hospital treatment compared to patient with typical symptoms and/or without comorbidities (Manfrini et al., 2016). These factors may contribute negatively to the prognosis of women with CHD. While younger (<45 years) female MI patients without chest pain have higher hospital mortality than their male counterparts (Canto et al., 2012), (older) age may mask gender differences (Manfrini et al., 2016), and contribute too little attention to their causes.

There were examples in our study of false-negative diagnostic tests (ECG, angiography and ultrasound) contributing to misdiagnosis. Angina with normal angiographic results is

more common in women than in men (Gopalakrishnan, Ragland, & Tak, 2009). This often leads to searching for a non-cardiac etiology. However, imaging studies have shown a higher incidence of non-occlusive CHD in women (Gopalakrishnan et al., 2009). Women with MI are also more likely than men to have non-specific ECG-changes and symptoms (Gopalakrishnan et al., 2009). It has also been suggested a higher prevalence of MI with normal angiograms, the cardiac syndrome X, among female versus male patients. However, this was not supported by a review study, although they concluded that prevalence rates were uncertain due to a wide variety in the definition and criteria of cardiac syndrome X (Vermeltfoort et al., 2010). It has been argued that diagnostic tests are based on the physiology of men, and may lack sensitivity and specificity to detect women's CHD (Rollini, Mfeukeu, & Modena, 2009). This calls for an awareness of the physiological differences between males and females in the interpretation of the diagnostic tests and assessments (Papakonstantinou, Stamou, Baikoussis, Goudevenos, & Apostolakis, 2013). In our study, patients described situations with doctors blindly trusting negative diagnostic tests, even in the presence of typical symptoms and known risk factors of CHD. A British study concluded that there exists a gender-based hierarchy related to all aspects of clinical management of angina pectoris in primary care (Crilly, Bundred, Leckley, & Johnstone, 2008).

Patients perceiving their symptoms as non-cardiac may delay help-seeking behavior (Welch et al., 2012), and this was also evident among patients in this study. Even when clearly suspecting a heart disease, some patients may resort to avoidant coping strategies (Bergvik, Sørli, & Wynn, 2010) including delayed help seeking, although these may apply to both female and male patients. Patients' perceived risk may often deviate from actual risks. Heart disease accounts for one-third of all deaths among women, while all cancers accounts for one-fourth, and breast cancer only for 3% (Townsend et al., 2015). However, more than 40% of women tend to worry more about other diseases such as cancer, and particularly breast cancer, than heart disease (Mosca, Mochari-Greenberger, Dolor, Newby, & Robb, 2010). Such misconceptions may contribute to delayed help seeking and referral to secondary care with negative implications for early adequate diagnostics and treatment (Gravelly-Witte, Jurgens, Tamim, & Grace, 2010; Mosca et al., 2010; Tod, Read, Lacey, & Abbott, 2001).

One of the patients trusted her GP who assumed that her stomach pain was due to gastric reflux problems. She did not seek further help. While correct information may help patients to act and respond adequately to symptoms, misdiagnosis may lead patients to ignore further symptoms and delay help seeking. Both doctors and patients may experience communications barriers in the management of CHD (D'Addario et al., 2015), and the prevailing dissatisfaction with doctors and the barriers for help seeking when having untypical symptoms are also reported in previous studies (Frich, Malterud, & Fugelli, 2006; Frostholm et al., 2005; Ha & Longnecker, 2010; McSweeney et al., 2005; Murray, O'Farrell, & Huston, 2000). Inadequate patient-physician relations may contribute to delayed treatment and patients' reluctance to seek help may reflect a concern that health-care providers may ignore their complaints and perceive them as "worriers" (Frostholm et al., 2005). Describing diffuse and multiple symptoms can be difficult, and the diagnostic uncertainties may contribute to patient unmet expectations resulting in more worried and less satisfied patients (Jackson & Kroenke, 2001). Comorbidities may complicate the situation even further, and increase the risk for misunderstandings and dissatisfaction. Our

results demonstrate how women with CHD may experience communicative difficulties with their GPs even when presenting typical CHD symptoms, and how this may delay adequate diagnosis and treatment and, consequently, health outcomes (Schoenberg, Peters, & Drew, 2003).

#### 4.1. Limitations

This qualitative study of nine participants in northern Norway may add to the understanding of how female patients may experience and make sense of their symptoms. However, we must be cautious in generalizing the results. Limitations may include the stressful situation related to the admission and imminent surgery, the age of the women (five  $\geq$  70 years), and local variations in GPs' level of awareness of gender differences in CHD. As CHD-related morbidity and mortality rates, gender differences, and the healthcare system tend to vary across countries (Puddu, Schiariti, & Torromeo, 2016; Townsend et al., 2015), future studies should include intra-European comparisons.

#### 4.2. Conclusions

Participants in the present study expressed a widespread frustration with their GPs' ignorance of their symptom descriptions, diagnostics and treatment approach. These problems may in particular relate to inadequate knowledge of gender differences in CHD symptoms and poor doctor–patient communication. Patient-centered communication may reduce the negative effects of inadequate knowledge and improve patient satisfaction and quality of care for women with CHD.

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