Life is lived forwards and understood backwards – Experiences of being affected by acute coronary syndrome: A narrative analysis

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Abstract

Background: Patients affected by acute coronary syndrome (ACS) report several symptoms subsequent to their discharge from hospital. These symptoms prolong their sick leave and complicate their return to the normal activities of everyday life. To improve health outcomes and establish quicker recovery for these patients, there is a need to better understand patients’ perceptions of their illness.

Objective: To explore patients’ experiences of ACS during their hospital stay.

Design: A qualitative interpretative interview study was conducted among patients during their hospitalization for ACS.

Setting: The study was performed in two designated coronary care units at a hospital in Sweden.

Participants: Twelve participants (five women and seven men; age range, 45–72 years), hospitalized with a diagnosis of ACS, were included in this study.

Methods: Patient narratives were recorded and transcribed. The records were later analyzed using a phenomenological hermeneutic approach.

Results: Patient experiences of ACS were formulated into one main theme: “awareness that life is lived forwards and understood backwards”. Two minor themes predominated in this main theme. The first was a sense of “struggling to manage the acute overwhelming phase”, which included four sub-themes: onset of life-threatening symptoms; fear and anxiety; being taken by surprise; and experiencing life as a hazardous adventure. The second theme was “striving to obtain a sense of inner security”, which also included four sub-themes: searching for and processing the cause and its explanation; maintaining a personal explanation; dealing with concern and uncertainty; and having a readiness to negotiate with life-pattern activities.

Conclusions: Hospitalized patients affected by ACS consider the cause of the onset and prepare to optimize their future health. These patients construct personal models to explain their disease, which may persist throughout continuum of care. One way to improve health outcomes for patients with ACS is to establish a shared knowledge about the illness and formulate personal care plans that cover the hospital stay as well as possibly extending into primary care after discharge, based on the patients’ point of view.

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What is already known about the topic?

- Cardiovascular disease, which includes coronary heart disease, is one of the leading causes of mortality and morbidity worldwide.
• Patients with acute coronary syndromes (ACS) report various symptoms after discharge from hospital which complicates the return to everyday life.
• Healthcare professionals and patients with ACS are non-concordant in terms of information about medication and the rehabilitation after an ACS event.

What this paper adds

• Patients with ACS are already prepared during the hospital stay to discuss their forthcoming goals.
• Patients affected by ACS are capable during hospitalization to construct personal models which serves as an explanation for being affected of the disease.
• Healthcare professionals need to pay attention to patient perspectives and through a carefully performed dialog formulate a personal care plan for each patient with ACS.

1. Introduction

During recent decades, coronary heart disease (CHD) mortality rates have gradually declined in Sweden (Dudas et al., 2012) as is the case for most northern and western European countries. However, in some of these countries, this reduction is beginning to plateau. Reductions in cardiovascular disease (CVD) are the result of improvements in primary prevention, resulting from the adoption of a healthier lifestyle among the general population. CVD causes over 4.3 million deaths annually in Europe and is still the main cause of death for women and men in almost all European countries. Moreover, CHD by itself is the main cause of mortality in Europe before the age of 75 as well as 65 (Rayner et al., 2009).

Acute coronary syndrome (ACS) manifests as clinical signs and symptoms of myocardial ischemia: unstable angina pectoris (UAP), non-ST-elevation myocardial infarction (NSTEMI) and ST-elevation myocardial infarction (STEMI). ACS represents the third most common cause of long-term illness in Sweden (Register of Information and Knowledge about Swedish Heart Intensive care Admissions [RIKS-HIA], 2007). The Swedish National Board of Health recommends sick leave for approximately 4 weeks after hospitalization for ACS (The National Board of Health and Welfare, 2007). However, 2007 statistics showed that the proportion of patients still on full-time sick leave 8 weeks after ACS was reported to be nearly 40% and, after 1 year, approximately 25% of patients in Sweden required part- or full-time sick leave related to their ACS episode (RIKS-HIA, 2007). The perceived work performance appears to be associated with age, physical function, perceived disease severity and symptom burden (Ellis et al., 2005). Patients’ perception of their illness influences health outcomes and has an important role in whether they return to work after an ACS event (Petrie et al., 2002). Although patients will recover physically from the myocardial injury, some may experience residual symptoms that cause suffering and prevent their return to work (Alsen et al., 2010).

Symptoms related to ACS cover a wide spectrum. Chest pain is the most commonly reported symptom of ACS in both men and women. However, there are a variety of other symptoms also associated with impending ACS, including pain in the arm, shoulder, neck and back; fatigue; sweating; nausea; and shortness of breath (Berg et al., 2009; Coventry et al., 2011; O'Donnell et al., 2012). Men, especially younger, are more likely to be affected by ACS (Coventry et al., 2011). During the onset of ACS, women are reported to experience several and often more atypical symptoms than men (Berg et al., 2009; Coventry et al., 2011). Inconsistencies have also been reported for gender differences in pre-hospital delay at the onset of ACS (Coventry et al., 2011). Many patients diagnosed with ACS report persistent fatigue (with or without concomitant depression) as a clear symptom that can have a negative impact on daily life (Alsen et al., 2010). Moreover, patients with diseases such as ACS report that they feel confused about the treatment and the severity of their disease (Attebring et al., 2005; Roebuck et al., 2001) and experience fear, anxiety and uncertainty during the acute phase of their disease as well as after discharge from hospital (Frasure-Smith et al., 1997; Jensen and Petersson, 2003; Svedlund et al., 2001).

Healthcare professionals and patients do not always have the same priorities regarding what information is most important to consider (Timmins, 2005). Studies have reported that there is often a failure to provide patients with ACS the appropriate information about their condition, and noticeably shorter hospital stays after ACS may lead to a lack of adequate information after discharge (Oterhals et al., 2006). Patients also experience conflicting information about their medication(s), resulting in patient dissatisfaction and doubt concerning the treatment decisions and competence of healthcare professionals (Dunckley et al., 2007). There is a well-known discrepancy in patient adherence to cardiovascular medication(s) (Calvert et al., 2012), which is also seen during rehabilitation after ACS. The importance of secondary prevention programs aimed at reducing risk factors and improving the functional status and quality of life in patients with ACS is well-studied (Clark et al., 2007). However, these programs will remain ineffective for patients that fail to comply with the programs; a common problem according to several studies (French et al., 2006). One explanation for this lack of compliance is related to patients’ own beliefs about their illness, which influences their health behaviors and outcomes after an ACS event. Previous studies reported that patients who viewed their condition as controllable were more likely to attend cardiac rehabilitation (French et al., 2006). Consequently, there seems to be a gap in healthcare between the care that each patient with ACS is offered and the care that is actually accessed by the patient. It is essential to reduce this discrepancy in the healthcare system and strengthen the interaction between healthcare professionals and patients with ACS to reduce suffering, improve concordance between healthcare professionals and the patients and establish better conditions for these patients to return to work or other desired activity. The purpose of this study was to explore patients’ experiences of ACS during their hospital stay with these goals in mind.

2. Method

The lived experience is personal but it is possible to take part in peoples’ experiences by interpreting narratives as
texts (Ricoeur, 1976). To understand and decipher patient narratives, a phenomenological hermeneutic approach was used, inspired by Ricoeur’s interpretation theory (Lindseth and Norberg, 2004). The method involves interpreting the meaning of a text in a structural and comprehensive way and has been developed over the past two decades and subsequently been used in several studies (e.g. Ekman and Skott, 2005; Svedlund et al., 2001).

2.1. Patients and setting

The participating patients were selected from two coronary care units (CCUs) at a university hospital in the western part of Sweden, which serves a population of almost one million people. To ensure a cohort consisting of both men and women and a broad age range, a strategic sample was applied. The following inclusion criteria were used: (a) a diagnosis of ACS or suspected ACS (working diagnosis) made on the basis of symptoms and electrocardiographic changes and/or confirmed by an abnormal elevation of cardiac enzyme levels; (b) referred for coronary angiography; (c) hospitalized in CCU; and (d) having a physical and mental capacity to participate in an interview-based study during their hospital stay.

Patient characteristics are described in Table 1. Twelve patients with ACS, comprising five women and seven men aged 45–72 years (median age, 62.0 years) were included. Most patients were married and employed. The length of hospital stay ranged between 4 to 14 days. At discharge, all patients had been diagnosed with ACS as their main diagnosis, with seven patients diagnosed with NSTEMI/STEMI (ICD 10) and five patients diagnosed with UAP (ICD 10).

2.2. Ethical consideration

Patients were invited to participate by a registered nurse (RN) at the CCUs when they were considered as clinically stable. None of the patients who were asked to participate declined. The patients gave their informed consent to participate in the study, which was approved by the Regional Ethics Committee and conformed to the Helsinki Declaration. The patients were informed that if they felt that some issues were too sensitive to discuss they could withdraw from the study at any time. Patients were also offered to consult with a counselor if required. The interview responses were treated with full confidentiality.

2.3. Interviews

The interviews were carried out by the first author or by a designated RN who was affiliated with the research unit at the hospital and familiar with the aim of the study. All interviews were performed during hospitalization in the patients’ rooms or in a private room near the CCU. The aim of the interview was explained to the interviewees who were encouraged to speak freely about their experiences of being affected by ACS. To encourage narration, the patients were asked broad, open-ended questions. The opening question was: “Could you please tell me what happened and how you felt when you were admitted to hospital?” The interviewer listened to the interviewees and their narrations were tape-recorded and later transcribed verbatim (mean time for each session was 25 min). Throughout the interview, to obtain comprehensive responses, the interviewer would interject with follow-up questions, such as: “Can you please tell me more about that?”, “Can you give me an example?” or “How did you feel?”. The interviews were conducted until the authors considered the research question to be answered in full.

3. Interpretation and findings

The interpretation of the narration consisted of three interrelated phases: naive reading, structural analysis and comprehensive understanding (Lindseth and Norberg, 2004). First, the narratives were read repeatedly to obtain an immediate sense and broad picture of their contents. Next, each text section was read specifically and the meaning units were identified and excerpted from the text. These units were critically reviewed in relation to the naive understanding. Similar patterns were then determined and sub-themes created to formulate the themes. We adopted a transparent and critical approach to our pre-understanding, which included the clinical experiences from cardiac care (second and third author) and secondary prevention in primary care (first author). We regularly reflected upon and discussed different interpretations of the text. In the final

Table 1

<table>
<thead>
<tr>
<th>RNr</th>
<th>Gender</th>
<th>Age</th>
<th>Civil status</th>
<th>Work status</th>
<th>Diagnosis at discharge</th>
<th>HDI</th>
<th>LOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female</td>
<td>62</td>
<td>Married</td>
<td>Working</td>
<td>I21.4B Acute subendocardial infarction, diaphragmal</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
<td>63</td>
<td>Married</td>
<td>Retired</td>
<td>I21.4 Acute subendocardial infarction</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>Female</td>
<td>63</td>
<td>Married</td>
<td>Working</td>
<td>I20.0 Unstable angina pectoris</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>Female</td>
<td>72</td>
<td>Married</td>
<td>Retired</td>
<td>I21.1 Acute transmural diaphragmal infarction</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>5</td>
<td>Female</td>
<td>59</td>
<td>Married</td>
<td>Working</td>
<td>I20.0 Unstable angina pectoris</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>6</td>
<td>Male</td>
<td>62</td>
<td>Married</td>
<td>Working</td>
<td>I21.4 Acute subendocardial infarction with non-specific localization</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>7</td>
<td>Male</td>
<td>55</td>
<td>Married</td>
<td>Working</td>
<td>I20.0 Unstable angina pectoris</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>Male</td>
<td>65</td>
<td>Married</td>
<td>Retired</td>
<td>I21.1 Acute Q-wave infarction inferior</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>9</td>
<td>Male</td>
<td>45</td>
<td>Married</td>
<td>Working</td>
<td>I21.4 Acute subendocardial infarction</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>61</td>
<td>Married</td>
<td>Working</td>
<td>I20.0 Unstable angina pectoris</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>11</td>
<td>Male</td>
<td>62</td>
<td>Living alone</td>
<td>Working</td>
<td>I21.1 Acute transmural diaphragmal infarction</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>12</td>
<td>Male</td>
<td>56</td>
<td>Married</td>
<td>Working</td>
<td>I20.0 Unstable angina pectoris</td>
<td>5</td>
<td>9</td>
</tr>
</tbody>
</table>

RNr, respondent number; HDI, hospital day for interview; LOS, length of hospital stay.
step, the whole text was re-read and critically interpreted, including the authors’ pre-understanding, naive reading and structural analysis, to formulate a comprehensive understanding of the narrative. This interpretation was carried out by the first author but discussed and validated by the co-authors.

3.1. Structural analysis

There was one overriding theme formulated: “awareness that life is lived forwards and understood backwards”. From this main theme, we derived two minor themes: (1) struggling to manage the acute overwhelming phase and (2) striving to obtain a sense of inner security. These themes were discerned from the text during the structural analysis and are described in more detail in Table 2 with the presented sub-themes. To illustrate the sub-themes, meaning units are given as examples below.

3.1.1. Struggling to manage the acute overwhelming phase

A diagnosis of ACS means that patients struggle to manage the acute overwhelming phase including the following sub-themes: onset of life-threatening symptoms; fear and anxiety; being taken by surprise; and experiencing life as a hazardous adventure.

3.1.1.1. Onset of life-threatening symptoms. The cardiovascular event causes different unpleasant symptoms, with chest pain as the most frequent and dominant symptom: “…the first pain was insurmountable, so to speak” (Respondent 6). Chest pain intensity levels vary and were described by patients as both “compressing” and “stabbing”, with or without radiation to arm and back. Other symptoms mentioned were breathlessness, sweating, fatigue and “air hunger” or out of breath, which could induce feelings of panic: “…since you could not breathe properly, you got a little panicked, actually” (Respondent 4). The symptoms were characterized as appearing either suddenly or gradually and developing from being unpleasant to being excruciating and life-threatening: “…I had pain in my chest and became short of breath very quickly, and it got worse and worse and worse until this Saturday, then, then I realized it was something really wrong. The pain did not disappear” (Respondent 10).

3.1.1.2. Fear and anxiety. Patients experienced fear and anxiety associated with the cardiovascular event, which were linked to the onset of life-threatening symptoms, such as chest pain. Fear and anxiety regarding ACS could arise at home where the patients associated their symptoms with some other less serious conditions: “…it’s probably side effects of my new blood pressure medication” (Respondent 5) or “…you would hope for the best that it is not the heart” (Respondent 7). A fear of death begins to appear during admission to hospital: “And then you become afraid that it will go ‘bang’ and then it will be over, because you want to live happily, life is dear to you. You want to see your children and grandchildren grow up” (Respondent 1). The fear and anxiety also occur once the patients have been admitted to hospital. The patients felt that something was wrong and they were afraid of losing control since they were dependent of the healthcare professionals to survive. These emotions were related to having to undergo examinations and surgeries: “So, I hope they can fix it with the balloon burst… I would definitely not like them to open me up” (Respondent 10).

3.1.1.3. Being taken by surprise. The ACS event involved an element of surprise for some patients: “I wasn’t prepared for a heart attack. I thought that it was a little sneaky, that it would appear in that way without me having reacted more to it” (Respondent 6). They felt that the onset of the illness was unexpected, irrespective of whether they had a previous history with cardiovascular disease: “…just that I had a heart attack now, that was not on my map. I take so much medication that I thought I was protected from getting a myocardial infarction!” (Respondent 2) or not “…this was not in my world of thoughts at all, that I should have a problem with my heart” (Respondent 4).

3.1.1.4. Experiencing life as a hazardous adventure. Having a diagnosis of ACS also meant that these patients realized the unpredictability of life: “And, I mean, after you have had so much pain, and then they’ve gone into the heart and done something, and the pain decreases and may disappear, then you know how fragile you are” (Respondent 1). Patients also acknowledged the vital function of the heart: “…when a heart attack strikes, it’s like ‘bam’ end… So, therefore, it’s quite shocking if you, yourself, suffer from it” (Respondent 3) or as another patient expressed: “A heart attack, then you’re almost dead” (Respondent 12).

3.1.2. Striving to obtain a sense of inner security

The text discloses that these patients are striving to obtain a sense of inner security, which we were able to divide into the following subthemes: searching for and processing the cause and its explanation; maintaining a personal explanation; dealing with concern and uncertainty; and having a readiness to negotiate with life-pattern activities.

3.1.2.1. Searching for and processing the cause and its explanation. The patients spent much time and energy considering the causes and seeking explanations for their disease. Heredity and several lifestyle factors such as stress, smoking, obesity and poor health, were self-evident as potential causes of the disease: “I strongly believe that stress, ill health and not feeling well emotionally affect the onset of the disease” (Respondent 1) or “So, I think it’s in the
genes, so I’ve been thinking that perhaps it may end up like this” (Respondent 8). These responses indicate that even if the onset of the disease in the first place was unexpected for the patients, they may, after a brief period, reflect on heredity as a possible explanation. It was also noticed that the patients experienced some unfairness: “...why is it that I, in particular, have been affected by this...” (Respondent 3). Most patients felt that it would help if they received an explanation, something to blame it on, even if they concluded that they themselves were to blame: “…yes, but it’s a little easier actually if you get an explanation... I can’t blame anyone else that I got this, it’s my own, my own fault, so to speak” (Respondent 3).

3.1.2.2. Maintaining a personal explanation. Patients had their own view of the onset of disease, wherein they clarified cause and effect: “But then I understand that these three months have been very tight when it comes to stress on my body” (Respondent 11). In a few patients, they seemed to have a premonition that there was something going on: “Work has been stressful so I have felt within me that there’s something not quite right, this is wrong, something is not right” (Respondent 5). Some patients identified as a key point that they themselves, rather than the healthcare professionals, could understand and explain why they had been affected by ACS: “Because then it feels like, now I, now I come to the conclusion myself… Not that there’s a doctor that tells me that this is due to this and this, instead this is what I myself believe…” (Respondent 3). It was important for the patients to form their own opinion: “I think it’s important to embrace your own model related to the disease because you get so much information” (Respondent 12).

3.1.2.3. Dealing with concern and uncertainty. Patients reported a concern and uncertainty about the initial stages, even before the patients knew the cause of the symptoms: “...then I started to be suspicious, that it was perhaps a little more serious than I had expected” (Respondent 6). This could also be linked to when they were admitted to hospital: “…I lay there on the bed, was tired, had pain and could not relax...you feel an uncertainty” (Respondent 1). Patients were also concerned about how they would feel and what would happen after their discharge from the hospital: “But I do not know how I will react when I get home” (Respondent 8) or “…a heart attack is quite overwhelming, there are many questions circulating, and it might not come up just when you are in it but it will come later many times” (Respondent 9).

3.1.2.4. Having a readiness to negotiate with life-pattern activities. The cardiac event was seen as an opportunity to restart life again: “…now I have the chance...to find out as much as possible about how to avoid worsening the condition of my blood vessels...I want to do what I can” (Respondent 12). The patients saw opportunities, created conditions and demonstrated a motivation to get started with lifestyle changes: “I hope they do so I can quickly return and be able to keep on with physical activity” (Respondent 6) or “The only way now is to not smoke” (Respondent 4). Some patients were also adjusting to and focusing on returning to work or other desired activities as soon as possible: “…I expect that I will return to my work fairly quickly” (Respondent 6) or “I plan to spend time and go out for walks with my children…and as I feel know I would like to start work again” (Respondent 11).

3.2. Comprehensive understanding

The main theme from this study is formulated in the metaphor of being aware that life is lived forwards and understood backwards. In contrast to everyday life, ACS is an event that sets this notion to the extreme as it leads to a sudden awareness of life’s fragility. Patients with ACS seem to have a strong need to link the past with the future to find an understandable explanation for their illness and, as a result of the event, to optimize their health conditions for the future. Our interpretation of the patients’ narratives suggests that patients with ACS are processing the perceived acute overwhelming phase at the same time as they are trying to obtain a sense of inner security. Below, this interpretation as well as the other themes will be discussed thoroughly and in relation to other studies within the research area.

4. Discussion

When struggling to manage the acute overwhelming phase, patients reported a variety of symptoms, the most common being chest pain, as reported previously (Berg et al., 2009; Coventry et al., 2011; O’Donnell et al., 2012). Chest pain, breathlessness and fatigue have a negative influence on patient health and quality of life after discharge from hospital (Roebuck et al., 2001). Consistent with previous findings, the onset for most of the patients during the acute phase was unexpected (Jensen and Petersson, 2003) and caused concern and uncertainty during hospitalization. These feelings have been shown to persist after discharge from hospital (Bergman and Berterö, 2003; Hanssen et al., 2005; Jensen and Petersson, 2003), and our study supports the findings of others with evidence of concern and uncertainty during hospital stay and at the post-discharge time. An early intervention starting with a thorough dialog and discussion with the healthcare professional may be beneficial to reduce these issues (Jensen and Petersson, 2003).

ACS was experienced as a hazardous adventure that made the patients more aware of life’s fragility, and the onset of symptoms was experienced as life-threatening. The symptoms induced fear and anxiety, which have been reported to be influential factors, both during onset and during rehabilitation after ACS (Frasure-Smith et al., 1997; Jensen and Petersson, 2003; Roebuck et al., 2001). Patients who rate their anxiety as high possess lower levels of belief about adjusting their lifestyle in response to health threats such as ACS (McKinley et al., 2009). Anxiety may also imply an increased risk of in-hospital complications, but the results are ambiguous (McKinley et al., 2012). The sub-theme fear and anxiety implies an increased risk of losing control since patients become dependent upon healthcare professionals to survive. This perceived lack of control may increase the occurrence of in-hospital complications (McKinley et al., 2012). Alsén et al. found that ACS tended
to be viewed as more chronic over time, and associated with a reduced perception of having control over the disease. As part of the rehabilitation program to facilitate healthy behavior, one strategy is to increase patient perception of personal control (Alsen et al., 2010).

The diagnosis of ACS seems to imply a process where the patients are striving to obtain a sense of inner security. They almost immediately start to reflect on the causes and explanations of their disease, which suggests that, during the hospital stay, they are already prepared to consider the cause of the onset and the consequences for their future. Most of the patients in our study were unprepared for the disease onset, they were taken by surprise, which often was related to being previously healthy or being on so much medication that they considered themselves to be protected from an ACS event. During the onset of ACS, patients interpreted the symptoms as being related to something less serious than the heart or as a side effect of their medication(s). This raises the need to take into account patients’ notions of cardiac candidacy and their beliefs about their condition and treatment to improve health outcomes after an event of ACS (Banner et al., 2012; Lockyer and Bury, 2002). For healthcare professionals, this means that it is a prerequisite to share knowledge with patients about the illness to build a foundation for continued recovery and rehabilitation (Granger et al., 2009). Attebring and co-workers emphasized the importance of concordance between healthcare professionals and patients with regard to the dissemination of information about their medication(s) to reduce the risk of confusion among patients about how to take their medication(s) (Attebring et al., 2005). A more focused approach on the patient as a person seems to increase concordance between healthcare professionals’ prescriptions and patients’ perceptions toward their cardiovascular medication(s) (Calvert et al., 2012). Furthermore, it is important to consider the existence of gender-specific differences in the experience and recovery from ACS, which is described in the literature as a disease that usually affects men (Lockyer and Bury, 2002). This also highlights the importance of taking into account a patient’s beliefs, from a gender perspective since ACS is a major cause of mortality even among women.

Another interpretation of the narratives is that patients also negotiate with their life-pattern activities, such as starting to exercise or setting other goals, such as returning to work or other desired activities. This is important to keep in mind, since rehabilitation programs sometimes do not commence until a couple of weeks after discharge. Furthermore, these patients are reported to request support and follow-up during the first weeks of discharge from hospital (Hanssen et al., 2005), a period determined to be most distressing for patients with ACS (Jensen and Petersson, 2003). This finding supports the importance of initiating the rehabilitation process during the hospital stay. Most of the patients in our study were employed and aimed to return to work as soon as possible. In contrast, Bergman and co-workers found that some patients with ACS may be either unwilling or unable to return to full-time work, which may be due to the fact that these interviews were performed after discharge from hospital (Bergman and Berterö, 2003). In the present study all interviews were collected during the hospital stay. There is sometimes a risk that individuals distance themselves from work once they are home, making it harder to return to work. Moreover, patients’ own illness perceptions probably influence whether they return to work after an ACS event (Petrie et al., 2002), this further underlines the importance of the need to support patients before discharge from hospital. An understanding of the factors that influence patients’ choices may facilitate healthcare professionals in guiding patients with ACS to the most appropriate cardiac rehabilitation (Wingham et al., 2006) and improve concordance between healthcare professionals and patients (McKinley et al., 2009; Wingham et al., 2006).

The sub-theme maintaining a personal explanation can be interpreted as a cognitive representation of one’s illness, which, based on the findings in this study, also seems to include patients with ACS. The explanatory model can be described as personal beliefs used to recognize, interpret and respond to a specific illness experience, which helps patients to cope with and understand both their illness and disease (Kleinman, 1980; Leventhal et al., 1998). It can affect patients’ choices of a future lifestyle, whether healthy or not (McSweeney et al., 1997). An interesting finding in this study is that some patients tended to rely more on their own explanation of the disease rather than the one given by the healthcare professionals. Hence, there are apparent differences between the prescriptions of various healthcare professionals, which are often generalized and associated with a diagnosis rather than each patient’s explanatory model. As such, healthcare professionals need to acknowledge patients’ explanatory models and develop a personal care plan based on these models. Person-centred care has been shown to result in important benefits for patients and clinics in general, in addition to meeting patient resources, motivations and needs (Dudas et al., 2013; Ekman et al., 2012; Meterko et al., 2010).

5. Strengths and weaknesses

The present study was limited to a small sample size, which is characteristic of qualitative methods. The purpose of using the phenomenological hermeneutics approach was to interpret experiences based on an in-depth analysis of single cases rather than to generalize across a large number of cases. The interviews were conducted by the first author or an RN affiliated with the research unit at the hospital. Neither the first author nor the RN had clinical experience in cardiac care in hospitals; we assumed that this might offer an unbiased interview process. While it is less favorable that the interviews and sets of follow-up questions were conducted by two different persons, the interviewers gave the interviewees the same set of instructions and commenced with the same opening question, with similar follow-up questions as necessary. In a qualitative study such as this, credibility lies in the quality of each interview rather than the number of samples; this was achieved by interviewing patients of both genders over a large age range and with the use of follow-up questions tailored to each specific story to clarify the findings. All 12 interviews were conducted
during hospitalization, ensuring that all patients were at a similar timeline in terms of generating their thoughts about the disease, with a clear ability to recall the event. When performing a phenomenological hermeneutical interpretation we do not expect to find one single universal truth, rather to search for possible meanings in a continuous process. There is always more than one way to analyze and interpret data and the results of this study represent one of several possibilities (Ricœur, 1976). However all possible interpretations are not equally probable. In order to end up with such a truthful interpretation of the narrative as possible all authors discussed the themes and sub-themes and considered competing interpretations until an agreement was reached. All authors have approved the presented findings. Nevertheless it is possible that other authors might have found other perspectives or themes if they had been involved during interpretation. The presented findings exemplify the experiences of patients with ACS, which can serve as a basis for future intervention studies and further dialog in the clinical setting where applicable.

6. Conclusions

The findings of this study highlight that patients with ACS already, at a very early stage during hospitalization, form their own understanding of their illness and prepare to sustain their future health. The findings also indicate that these patients construct personal models to explain their disease, which remain during their hospital stay and may persist even longer. To enhance the interaction between healthcare professionals and patients with ACS, we suggest that healthcare professionals systematically consider the patient’s perspective. This challenges healthcare professionals to replace standardized teaching methods, which do not always allow for individual or gender-specific differences. To move from knowledge to action, there is an explicit and continuous need for future intervention studies aimed at examining the effect of a person-centred approach in several diseases, not least in ACS.

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