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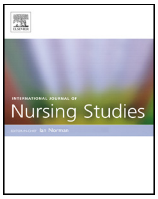

Life is lived forwards and understood backwards – Experiences of being affected by acute coronary syndrome: A narrative analysis

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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.

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.

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- 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 (Alsén 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 (Alsén 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 with 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