Patient-reported causes of heart failure in a large European sample☆

Ivy Timmermans [a,b,*], Johan Denollet [b,c], Susanne S. Pedersen [d,e], Mathias Meine [a], Henneke Versteeg [a]

[a] Department of Cardiology, University Medical Center Utrecht, Utrecht, The Netherlands
[b] CoRPS – Center of Research on Psychological and Somatic Disorders, Department of Medical and Clinical Psychology, Tilburg University, Tilburg, The Netherlands
[c] Department of Cardiology, Antwerp University Hospital, Edegem, Belgium
[d] Department of Psychology, University of Southern Denmark, Odense, Denmark
[e] Department of Cardiology, Odense University Hospital, Odense, Denmark

ABSTRACT

Background: Patients diagnosed with chronic diseases develop perceptions about their disease and its causes, which may influence health behavior and emotional well-being. This is the first study to examine patient-reported causes and their correlates in patients with heart failure.
Methods: European heart failure patients ($N = 595$) completed questionnaires, including the Brief Illness Perceptions Questionnaire. Using deductive thematic analysis, patient-reported causes were categorized into *physical*, *natural*, *behavioral*, *psychosocial*, *supernatural* and *other*. Clinical data were collected from medical records.
Results: Patients who did not report any cause (11%) were on average lower educated and participated less often in cardiac rehabilitation. The majority of the remaining patients reported physical causes (46%, mainly comorbidities), followed by behavioral (38%, mainly smoking), psychosocial (35%, mainly (work-related) stress), and natural causes (32%, mainly heredity). There were socio-demographic, clinical and psychological group differences between the various categories, and large discrepancies between prevalence of physical risk factors according to medical records and patient-reported causes; e.g. 58% had hypertension, while only 5% reported this as a cause. Multivariable analyses indicated trends towards associations between physical causes and poor health status (Odds ratio (OR) $= 1.41$, 95% confidence interval (95% CI) $= 0.95–2.09$, $p = 0.09$), psychosocial causes and psychological distress (OR $= 1.54$, 95% CI $= 0.94–2.51$, $p = 0.09$), and behavioral causes and a less threatening view of heart failure (OR $= 0.64$, 95% CI $= 0.40–1.01$, $p = 0.06$).
Conclusion: European patients most frequently reported comorbidities, smoking, stress, and heredity as heart failure causes, but their causal understanding may be limited. There were trends towards associations between patient-reported causes and health status, psychological distress, and illness perceptions.

1. Introduction

In developed countries, 1–2% of the general population suffers from heart failure, a chronic and debilitating disease characterized by tiredness, shortness of breath and peripheral and/or lung edema, caused by a structural of functional abnormality of the heart [1]. The prevalence of heart failure is still increasing, due to the aging of the population and improved treatment options leading more patients to survive a predisposing cardiac event [2,3]. Nevertheless, heart failure remains associated with an increased risk for morbidity and mortality, impaired health status and frequent hospital admissions [2,3].

After being diagnosed with a disease like heart failure, patients may develop mental representations about the characteristics of their disease (e.g. heart failure) and its causes [4–7]. According to Leventhal's common sense model of self-regulation, these representations are a reaction to situational stimuli (e.g. palpitations, chest pain, or dyspnea), and lead to the adoption of coping strategies. This model also implies that patients evaluate the efficacy of their mental representations and coping strategies in eliminating the situational stimuli, and adjust them if necessary [8]. Therefore, patient-reported causes play a crucial role in disease management, as they can influence if and what type of treatment patients seek, and the actions they take to manage and cope with their disease [6,9–11]. For example, if patients believe their disease was caused by a poor diet, they may be more likely to change their dietary habits.

Previous research has examined patient-reported causes of disease in a variety of patient populations using (purpose-designed) questionnaires or interviews and different coding approaches [12–21]. These studies showed that beliefs held by patients about the causes of their

disease are not necessarily consistent with medical and scientific knowledge. Also, it seems that patients with diseases for which causes are less clear (e.g. breast or gynecologic cancer, or chronic fatigue) are more likely to attribute it to external and uncontrollable factors like psychosocial stress factors in the past, and heredity [12,14,16,18], while patients with for example lung cancer, skin melanoma or chronic obstructive pulmonary disease (COPD) more often mention behavioral factors (e.g. smoking), perhaps as a result of common knowledge on the association between these diseases and health behavior [15]. Studies investigating patients with cardiovascular disease (i.e. coronary heart disease and myocardial infarction) also showed considerable variation in patient-reported causes (e.g. stress, lifestyle, health behavior, family history and aging), as well as a lack of concordance between actual risk factors and patient beliefs about causes [13,17,19–21].

To the best of our knowledge, patient-reported causes have never been studied in patients with heart failure. Since heart failure has a chronic and multifactorial nature, better insight into patient-reported causes may provide targets to improve coping behavior and treatment adherence, and enhance patient centered care [17,22]. Therefore, the aims of this study were to 1) describe patient-reported causes in a large European sample of patients with heart failure, 2) examine socio demographic, clinical, lifestyle and psychological correlates of these causes, and 3) examine if patient-reported causes are associated with health status, psychological distress, illness perceptions, and heart failure self-care behavior.

2. Methods

2.1. Study design and participants

The study sample consisted of 595 patients with heart failure, who participated in the large European randomized REMOTE-CIED study [23]. The REMOTE-CIED study was primarily designed to examine the patient perspective on remote monitoring in patients with heart failure with an implantable cardioverter defibrillator (ICD). Patients were recruited from 32 academic and general hospitals in France, Germany, the Netherlands, Spain and Switzerland between April 2013 and January 2016. All patients were between 18 and 85 years of age, suffered from symptomatic heart failure (i.e. left ventricular ejection fraction (LVEF) ≤35% and New York Heart Association (NYHA) functional class II or III at the time of implantation), and received a first-time ICD or cardiac resynchronization therapy defibrillator device (CRT-D) for primary or secondary prophylaxis at one of the participating centers. Patients were asked to complete an elaborative set of standardized and validated questionnaires 1–2 weeks post-ICD/CRT-D implantation. The study protocol was approved by the Medical Ethics Committee of all participating hospitals, and the study was conducted in accordance with the Declaration of Helsinki. All patients received written and oral information about the study and provided written informed consent.

2.2. Measures

Information on *socio demographic characteristics* was collected using purpose-designed questions in the questionnaire, and included age, sex, marital status (single versus having a partner), educational level (secondary school or lower versus tertiary school or higher) and employment status (employed versus unemployed).

Information on *clinical characteristics* was retrieved from patients' medical records at the time of implantation and entered into an electronic case report form by local researchers, and included NYHA functional class, heart failure etiology (ischemic versus non-ischemic), QRS duration, LVEF, atrial fibrillation, hypertension, diabetes mellitus, chronic obstructive pulmonary disease, renal disease (glomerular filtration rate < 60 ml/min/1.73 m^2), and anemia (hemoglobin value <8.6 mmol/l for males and <7.4 mmol/l for females). The 23-item Kansas City Cardiomyopathy Questionnaire (KCCQ) was used to measure *heart failure specific health status.*

The KCCQ measures physical limitations, symptoms, social functioning, and health related quality of life (e.g. "Over the past 2 weeks, how much has your heart failure limited your enjoyment of life?"). An overall summary score can be computed (0−100), with higher scores indicating better patient-reported health status. An overall summary score < 50 indicates poor health status. The KCCQ is a valid and reliable tool to assess patient-perceived heart failure specific health status [24]. The internal consistency of the KCCQ was good, with a Cronbach's alpha of 0.98 in the current sample.

Information on *health-related lifestyle characteristics* (i.e. body mass index, smoking status, use of alcoholic beverages, and participation in a cardiac rehabilitation program) was collected with purpose-designed questions in the questionnaire. Additionally, patients completed the 12-item European Heart Failure Self-care Behavior Scale (EHFScBS-12). The items on this scale are rated on a 5-point Likert scale from 1 'completely agree' to 5 'completely disagree' (e.g. "I weigh myself every day"). Total scores can be calculated (12–60), with higher scores indicating worse self-care behavior. This scale is a valid and reliable tool to measure heart failure specific self-care behavior [25], with a Cronbach's alpha of 0.72 in the current sample.

Patients' *psychological status* was assessed using multiple questionnaires. Patients were asked about their *use of psychotropic medication* (i.e. antidepressants, anxiolytics and/or hypnotics) and *psychological treatment* using purpose-designed questions in the questionnaire, as a proxy measure for prior or existing affective disorders. The 7-item Generalized Anxiety Disorder scale (GAD-7) was used to measure *anxiety symptoms*. Items on this scale are rated on a 4-point Likert scale from 0 "not at all" to 3 'almost daily' (e.g. "Over the last 2 weeks, how often have you felt nervous, anxious or on edge?"). The GAD-7 is a reliable and valid scale, with a Cronbach's alpha of 0.91 in this sample. A cut-off value of ≥10 was used to classify patients with clinically relevant anxiety symptoms [26]. The 9-item Patient Health Questionnaire (PHQ-9) was used to measure *depressive symptoms*. The items of this questionnaire mirror each of the 9 DSM-IV depression criteria and are answered on a 4-point Likert scale from 0 'not at all' to 3 'nearly every day' (e.g. "Little interest or pleasure doing things"). The PHQ-9 is a reliable and valid measure of depressive symptoms [27], with a Cronbach's alpha of 0.83 in the current sample. A cut-off score ≥ 10 was used to classify patients with clinically relevant symptoms of depression. The 14-item Type D Scale (DS14) was used to measure *Type D personality* (i.e. tendency towards negative affectivity and social inhibition [28]). The items on this scale are rated on a 5-point Likert scale ranging from 0 'false' to 4 'true' and can be divided into a 7-item negative affectivity subscale (e.g. "I am often irritated") and a 7-item social inhibition subscale (e.g. "I find It hard to start a conversation"). Type D personality is defined as a score of ≥10 on both subscales [28]. Cronbach's alpha was 0.88 for the negative affectivity subscale, and 0.85 for the social inhibition subscale in the current sample.

Patients' *beliefs about their heart failure* were measured using official non-modified translations of the first eight items of the B-IPQ [29]. Items (e.g. 'How much does your illness affect your life?', 'How concerned are you about your illness?', and 'How well do you think you understand your illness?') are rated on an 11-point Likert scale, and total scores range from 0 to 80. Higher scores reflect a more threatening view of heart failure. This questionnaire has good psychometric properties in patients with heart failure [30], and Cronbach's alpha in the current sample was 0.69.

Patient-reported causes of heart failure were measured with the ninth item of the BIPQ [29]. This is an open-ended question where patients themselves have to report the three most important causes of their disease (i.e. 'Please list in rank-order the three most important factors that you believe caused your illness. The most important causes for me: 1) … 2)… 3)…'). To analyze this item, the coding scheme from Duwe et al. [31] was used. Using both inductive and deductive thematic analyses, they established the following categories in a sample of older patients with hypertension: physical (e.g. diabetes mellitus), natural (e.g.