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Illness perceptions in patients with heart failure and an implantable cardioverter defibrillator: Dimensional structure, validity, and correlates of the brief illness perception questionnaire in Dutch, French and German patients

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ABSTRACT

Background: Patients' illness perceptions are associated with psychological wellbeing and can be measured with the Brief Illness Perception Questionnaire (B-IPQ). However, little is known about illness perceptions in patients with heart failure. We examined the dimensional structure, validity and clinical and psychological correlates of the B-IPQ in Dutch, French and German patients with heart failure and an implantable cardioverter defibrillator (ICD).

Method: European heart failure patients (n = 585) participating in the REMOTE-CIED study completed a set of questionnaires 1–2 weeks post ICD-implantation, including the B-IPQ. Information on clinical data was captured from patients' medical records.

Results: A two-factor structure (I = 'Consequences'; II = 'Control') represented 7 out of 8 B-IPQ items in the total sample and Dutch, German and French subgroups. The total B-IPQ had a Cronbach's α of 0.69, with the 'Consequences' subscale being more internally consistent (α = 0.80). Both the B-IPQ and its 'Consequences' subscale were significantly correlated with a number of psychological characteristics, but not with clinical characteristics. Multivariable logistic regression analysis indicated that threatening illness perceptions as measured with the total B-IPQ were associated with poor health status (OR = 2.66, 95%CI = 1.72–4.11), anxiety (OR = 1.79, 95%CI = 1.001–3.19), depression (OR = 2.81, 95%CI = 1.65–4.77), negative affectivity (OR = 1.93, 95%CI = 1.21–3.09) and poor ICD acceptance (OR = 2.68, 95%CI = 1.70–4.22).

Conclusion: The B-IPQ demonstrated good psychometric properties in Dutch, French and German patients with heart failure. Psychological factors were the most important correlates of patients' perceptions of heart failure, emphasizing the importance of targeting maladaptive illness perceptions in this population, due to their impact on patients' wellbeing and quality of life.

1. Introduction

According to Leventhal's common sense model of self-regulation, illness perceptions are cognitive and emotional representations of illness or health threats (e.g., heart failure) as a reaction to situational stimuli (e.g., palpitations, chest pain or dyspnea). These representations lead to the adoption of coping behaviors. Subsequently, the efficacy of the illness representations and coping behaviors is evaluated and adjusted if necessary [1]. Patients' cognitive illness perceptions are generally covered by five dimensions, and include beliefs about identity (ideas about name and symptoms), causes (ideas about origin), consequences (impact on life domains), timeline (ideas about duration), and cure or control (ideas about treatment and recovery) of their illness. Emotional perceptions consist of negative reactions, such as fear, anger or distress [1–3].

Illness perceptions play an important role in patient behavior and

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patient wellbeing. For example, Morgan et al. showed that illness perceptions were associated with psychological wellbeing and that they contribute more to psychological distress (i.e., anxiety and/or depression) than traditional covariates such as socio-demographic characteristics and functional status [4]. A meta-analytic review of 45 studies measuring illness perceptions in a wide variety of medical conditions indicated that the perception of more severe consequences and more physical limitations was associated with worse physical, role and social functioning, higher distress levels, and lower wellbeing and vitality. Longer timeline perceptions were associated with higher distress levels, lower role and social functioning and lower vitality as well. By contrast, higher perceived control was associated with better social functioning, more wellbeing, lower distress levels, higher vitality and better disease state [5]. Another systematic review showed an association between illness perceptions and survival in patients with end-stage renal disease [6], which further emphasizes the importance of patients' illness perceptions for managing chronic clinical conditions.

Heart failure is a common clinical syndrome, affecting 1–2% of the general population in developed countries, and due to an aging population and increased survival after acute cardiac events, the number of patients is growing [7,8]. Despite improved treatment options, heart failure is associated with a high risk for morbidity and mortality, impaired health status and frequent hospital admissions [7,8]. Heart failure patients who are at high risk for life threatening ventricular arrhythmias are preferably treated with implantable cardioverter defibrillator (ICD) therapy [9]. Both heart failure and living with an ICD may negatively impact psychological wellbeing, with significant prevalences of depression (10–60% for patients with heart failure and 5–41% for patients with an ICD) and anxiety (11–45% for patients with heart failure and 13–63% for patients with an ICD) [10,11]. Although illness perceptions may also play an important role in this context, little is known about these perceptions in patients with heart failure.

The Brief Illness Perception Questionnaire (B-IPQ) originated from the Illness Perception Questionnaire (IPQ) and Illness Perception Questionnaire-Revised (IPQ-R), and was designed for quick and simple assessment of illness perceptions [12]. The B-IPQ has been used in different populations, varying by age, illness type, country and language, with its psychometric evaluation indicating good concurrent and predictive validity, and sensitivity to change [13]. However, the psychometric qualities of the B-IPQ have not been investigated in patients with heart failure, nor for German and French translations of the B-IPQ [13].

The objectives of the current study were 1) to examine the dimensional structure of illness perceptions as measured by the B-IPQ, 2) to assess the psychometric properties of the Dutch, French and German translations of the B-IPQ, and 3) to identify the clinical and psychological correlates of threatening illness perceptions in a sample of heart failure patients with an ICD.

2. Methods

2.1. Study design and participants

The sample consisted of 595 heart failure patients with a first-time implantable cardioverter defibrillator (ICD), who participated in the REMOTE-CIED study [14]. The REMOTE-CIED study was a randomized trial primarily designed to examine the patient perspective on remote monitoring in heart failure patients with an ICD. Patients were recruited between April 2013 and January 2016 from 32 academic and general hospitals in France, Germany, the Netherlands, Spain and Switzerland. Consecutive patients receiving a de novo primary or secondary prophylactic ICD or cardiac resynchronization therapy defibrillator device (CRT-D) at one of the participating centers were screened for participation. Patients were aged between 18 and 85 years and suffering from symptomatic heart failure, defined as left ventricular ejection fraction (LVEF) $\leq 35\%$ and New York Heart Association (NYHA) functional class II or III at the time of implantation, with a higher NYHA functional class indicating more functional limitations. The Medical Ethics Committee of the participating hospitals approved the study protocol. The study was conducted in accordance with the Declaration of Helsinki, and all patients received written and oral information about the study and provided written informed consent.

3. Measures

For the participating patients, the first part of the REMOTE-CIED study consisted of the completion of a set of standardized and validated questionnaires at 1–2 weeks after ICD implantation (baseline, prior to randomization). The introductory page of the questionnaire informed the patients that the study was about their heart failure and ICD. Clinical data was collected from patients' medical records at time of implantation and entered in an electronic case report form by the local investigators at the participating centers.

Illness Perceptions were measured using official non-modified translations of the 9-item B-IPQ [12]. The scale consists of eight items rated on an 11-point Likert scale from 0 and 10. Five items are designed to assess cognitive illness representations, i.e. consequences ("How much does your illness affect your life?" with 0 = no affect at all, and 10 = severely affects my life), timeline ("How long do you think your illness will continue?" with 0 = a very short time, and 10 = forever), personal control ("How much control do you feel you have over your illness?" with 0 = absolutely no control, and 10 = extreme amount of control), treatment control ("How much do you feel your treatment can help your illness?" with 0 = not at all, and 10 = extremely helpful) and identity ("How much do you experience symptoms from your illness?" with 0 = no symptoms at all, and 10 = many severe symptoms). Two items are designed to assess emotional representations, i.e. concerns ("How concerned are you about your illness?" with 0 = not at all concerned, and 10 = extremely concerned) and emotions ("How much does your illness affect you emotionally?" with 0 = not at all affected emotionally, and 10 = extremely affected emotionally) and one item to assess illness comprehensibility ("How well do you think you understand your illness?" with 0 = don't understand at all, and 10 = understand very clearly). Item 3 (personal control), 4 (treatment control) and 7 (understanding) need recoding due to reversed scoring. For these eight items, the total score ranges from 0 to 80, with higher scores reflecting more threatening illness perceptions [12]. Patients with total scores in the upper tertile of the B-IPQ were classified as having a threatening view of their illness. The ninth question is open-ended and asks patients to list the three most important causal factors of their illness; this question is not included in the current analyses.

Information on *socio demographic characteristics* 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), and was collected by means of purpose-designed questions in the baseline questionnaire.

Clinical characteristics included cardiac resynchronization therapy, ICD indication (primary versus secondary prophylactic), 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 m2), and anemia (hemoglobin value < 8.6 mmol/l for males and < 7.4 mmol/l for females). Information on *satisfaction with care* was obtained through a visual analogue scale ($0 - 100$). The higher the score, the more satisfied a patient is with the received care from the cardiology unit.

Health status was measured with the 23-item Kansas City Cardiomyopathy Questionnaire (KCCQ). This questionnaire assesses 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?"). A summary score ranging