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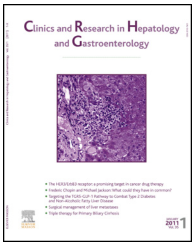

ORIGINAL ARTICLE

Quality of life and illness perception in primary biliary cirrhosis: A controlled cross-sectional study

Aurélie Untas[a,*], Emilie Boujut[a], Christophe Corpechot[b], Franck Zenasni[c], Olivier Chazouillères[b], Philippe Jaury[d], Raoul Poupon[b], Céline Buffel du Vaure[d], Serge Sultan[e,f]

[a] Laboratoire de Psychopathologie et Processus de Santé EA 4057, Institut Universitaire Paris Descartes de Psychologie, Université Paris Descartes, Sorbonne Paris Cité, 71, avenue Édouard-Vaillant, 92100 Boulogne-Billancourt, France
[b] Centre de Référence des Maladies Inflammatoires des Voies Biliaires, Inserm UMR_S938, AP—HP, Université Pierre-et-Marie-Curie Paris 6, Hôpital Saint-Antoine, 184, rue du Faubourg-Saint-Antoine, 75012 Paris, France
[c] Laboratoire Adaptation Travail Individu EA 4469, Institut Universitaire Paris Descartes de Psychologie, Université Paris Descartes, Sorbonne Paris Cité, 71, avenue Édouard-Vaillant, 92100 Boulogne-Billancourt, France
[d] Département de Médecine Générale, Université Paris Descartes, Sorbonne Paris Cité, Faculté de Médecine Cochin-Port Royal, 24, rue du Faubourg-Saint-Jacques, 75014 Paris, France
[e] Département de Psychologie, Université de Montréal, Montréal, Québec, Canada
[f] CHU Sainte-Justine, Montréal, Québec, Canada

Summary

Objective: The aim of this study was to understand better the quality of life (QOL) and illness perception in women with primary biliary cirrhosis (PBC) through a comparison with women having diabetes.

Methods: One hundred and ninety-four women took part in this study: 130 with PBC, 64 with type 2 diabetes. They were administered the SF-12 to measure QOL and the Brief Illness Perception Questionnaire to assess representations of their illness. Analysis of covariance with bootstrapping was used to compare QOL and illness perception scores by controlling age and mean disease duration.

Results: Physical QOL was significantly worse for women with PBC than for women with diabetes. Women with PBC felt their disease would last longer and reported more symptoms and concerns related to their disease than women with diabetes. Significant differences

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* Corresponding author. Tel.: +33 1 55 20 58 50.
E-mail address: aurelie.untas@parisdescartes.fr (A. Untas).

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were also observed for causes: women with PBC mainly reported autoimmune, emotional, unknown/unlucky and medical causes whereas women with diabetes reported mostly lifestyle and hereditary causes. Marginally significant differences were observed regarding consequences on daily life, feeling of control over the disease and emotional responses, which were shown to be worse in PBC. Mental QOL, treatment control and overall understanding of the disease was similar in both groups.

Conclusions: This study shows that women with PBC have a worse QOL and somewhat different illness perception than women with diabetes. Further research could help understand PBC specificities better in order to improve patient care, especially if factors such as fatigue or rarity of the disease explain these results.

Introduction

Primary biliary cirrhosis (PBC) is a chronic cholestatic liver disease of unknown etiology whose prevalence ranges from 100 to 400 per million people [1]. It occurs more in women (90%) and is most often seen in middle age. PBC is slowly progressive and can result in cirrhosis and liver failure. Initially asymptomatic, patients will often develop pruritus and fatigue over the course of the illness [2]. Quality of life (QOL) is altered in patients with PBC compared to control groups from the general population matched for sex and age [3,4]. Fatigue is the symptom that seems to have the greatest impact on QOL in this population [4,5]. Altered QOL is not specific to PBC and is observed in many chronic diseases, such as diabetes, chronic kidney disease and heart failure [6—8].

According to Leventhal's Self-Regulation Model [9], when people are facing an illness, they create their own representations in order to make sense of the problem and to cope with it. Illness perception is composed of both cognitive and emotional representations. Five main components have been identified in cognitive representation:

- *identity*, which is the label the person uses to describe the illness and the symptoms they view as being part of the disease;
- *consequences*, which are the expected effects and outcomes of the illness;
- *causes*, which are the personal ideas about the causes of the illness;
- *timeline*, which is the length of time the patient believes the illness will last;
- *cure/control*, which is the extent to which the patient believes that he/she can recover from or control the illness.

Emotional representation includes negative reactions such as fear, anger and distress. Studies among patients with various chronic diseases have shown that illness perceptions are associated with different outcomes such as QOL. For example, in patients with type 2 diabetes, negative beliefs about illness are associated with low physical and mental functioning [10]. To our knowledge, illness perception has never been studied in PBC.

In order to understand better the specificity of PBC, and particularly the experience of living with a rare disease, the aim of the present study was to assess QOL and illness perception in patients with PBC through a comparison with patients having a common chronic disease. Diabetes is one of the most widespread chronic diseases in the population with a worldwide prevalence of around 8.3% in adults in 2013 [11]. People with type 2 diabetes often have no symptoms at first and may have none for many years. Early symptoms may include fatigue, hunger and increased thirst. As mortality and morbidity is higher in diabetes than in PBC [12,13], we hypothesized that diabetes patients would have a lower QOL than PBC patients. Moreover, we hypothesized that illness perception would be different in PBC compared to diabetes because of the stigma of living with a rare organ-specific disorder [14]. As PBC occurs more in women (90%), we decided to focus our study on them.

Materials and methods

Participants and data collection

Sample 1: PBC patients

PBC patients were recruited through the Hepatology Department of Saint-Antoine Hospital (Paris, France) and through a specific French patient association dedicated to the fight against inflammatory biliary diseases (''Association pour la Lutte contre les Maladies Biliaires Inflammatoires'', ALBI), specifically PBC, primary sclerosing cholangitis and autoimmune hepatitis. At the Saint-Antoine Hospital, patients with PBC were identified by physicians. The study was presented during a medical consultation and questionnaires were given with a pre-paid return envelope. For the association, an email was sent to all members to present the study and invite them to take part through an online survey. The distribution and collection of the questionnaires were carried out between March and September 2012.

One hundred and fifty-seven patients with PBC took part in the study. For the purpose of the present research, PBC patients with autoimmune hepatitis overlap syndrome were