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The concept of Illness Identity in patients with Inflammatory Bowel Diseases

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Introduction

Inflammatory bowel diseases can have a lasting, substantial impact on patients' daily life and well-being. Due to the high symptom burden of inflammatory bowel diseases, the process of identity formation and the integration of Inflammatory bowel diseases into the self-concept can be challenging.

The concept of Illness Identity describes the nature and degree to which patients integrate a chronic illness into their self-concepts. Four distinct dimensions of Illness Identity can be differentiated with the Illness Identity Questionnaire: acceptance, enrichment, engulfment and rejection. Childhood trauma has been connected to inflammatory bowel diseases and perturbances in the self-concept. However, it is unclear if there are associations between childhood trauma and the formation of Illness Identity in patients with chronic diseases.

This study aimed to 1) assess the associations between childhood trauma and Illness Identity in patients with inflammatory bowel diseases 2) examine differences in childhood trauma and Illness Identity between patients with Crohn's Disease and patients with Ulcerative Colitis; 3) assess the associations between Illness Identity and psychosocial factors in inflammatory bowel diseases; 4) examine the associations between Illness Identity and response to biologic therapy in inflammatory bowel diseases and 5) to explore the stability of Illness Identity over time.

Material and Methods

Two samples of patients with inflammatory bowel diseases answered questionnaires regarding Illness Identity and further other biopsychosocial factors: sample 1 (n=209) was an anonymous online sample, and sample 2 consisted of 84 outpatients from the University Medical Centre Mannheim with active disease, before and three to six months after a change of therapy. Correlational and network analyses were performed to examine associations between clinical and survey data.

Results

1) Most bivariate correlations between childhood trauma and Illness Identity did not persist after controlling for other biopsychosocial factors in the network analyses, except for weak negative associations between acceptance and childhood trauma in sample 2 as well as a positive association between rejection and childhood trauma in sample 1. 2) Patients with Crohn's disease and Ulcerative Colitis did not differ regarding adverse childhood experiences and prevalence and distribution of the Illness Identity dimensions. 3) Illness Identity showed several associations with biopsychosocial factors and dimensions. A strong complex formed by the associations between engulfment and depressive symptoms, visceral sensitivity and quality of life emerged in both samples. 4) No associations were found between the Illness Identity dimensions and response to therapy at follow-up. 5) Exploratory analyses of the stability of Illness Identity in patients with inflammatory bowel diseases imply a higher degree of changes in Illness Identity in patients with inflammatory bowel disease than in other chronic diseases.

Discussion

This first examination of Illness Identity in patients with inflammatory bowel diseases reveals a similar distribution of Illness Identity dimensions as in previous studies on other diseases. It partly replicates findings regarding the Illness Identity dimensions' differential associations to psychosocial factors. To determine the directionality of the strong associations of the Illness Identity dimension engulfment to clinically relevant factors like quality of life, depression and visceral sensitivity, further studies should be performed to assess the role of Illness Identity as a potential therapeutic target.