

Patient Experience Analysis of an Online Community of Patients With Exocrine Pancreatic Insufficiency Due to Chronic Pancreatitis Using a Patient-Centered Observational Approach

C0006

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INTRODUCTION



Exocrine pancreatic insufficiency (EPI) is a condition caused by a deficit of functional pancreatic enzymes

- EPI is commonly secondary to chronic pancreatitis (CP)¹



Patients with EPI typically experience **malabsorption and/or malnutrition, including manifestations that may negatively affect quality of life (QoL)**¹



Although the prevalence of EPI is considered high but variable depending on etiology, **it is considered to be underdiagnosed and undertreated**¹

To understand the unmet need and therapeutic burden for individuals with EPI with CP, such as factors that affect treatment choices, QoL, and healthcare utilization outcomes, a two-pronged approach is currently being used involving:



1. A US-based registry with patients taking pancreatic enzyme replacement therapy



2. An online patient community with structured/unstructured data collection activities



Both approaches are being implemented to capture data/experiences to **better appreciate the patient experience, patient needs, and burden of illness**

OBJECTIVE



The goal of this analysis was to understand the patient's experience of CP with EPI and identify common themes discussed by members of the online community

METHODS



HealthUnlocked CP Community posts from January 13, 2021, to February 2, 2022, were reviewed

- A thematic analysis of community conversation outside of planned discussion questions and research events was conducted to determine common themes discussed by members

RESULTS

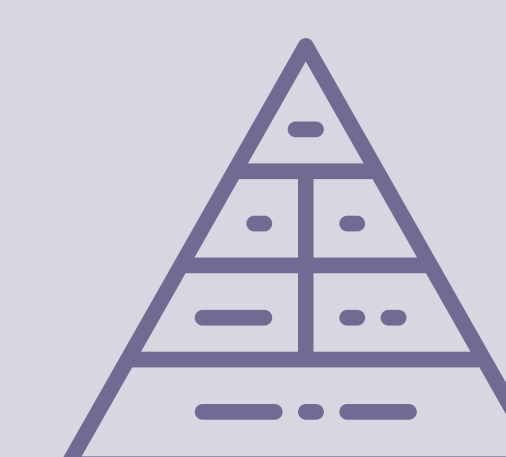
386 COMMUNITY POSTS WERE ANALYZED



PAIN

Members discussed how CP impacts their QoL, stating symptoms often prevent them from living a "normal life"

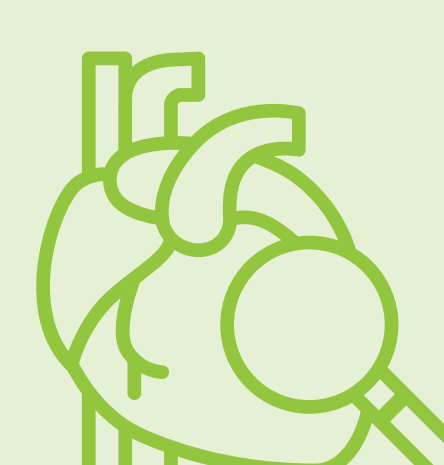
Members noted difficulty finding proper treatment options, which often prolonged pain



DIET

Members often experienced painful flare-ups with change in diet

Members found their CP symptoms were influenced by low fat diet, limiting alcohol consumption, vegan/vegetarian diets, herbal teas, and bland food



DIAGNOSIS

Members often found specialists to be the most helpful

Members shared frustrations during the diagnosis process

Members encountered misconceptions from providers and often looked for their concerns to not be dismissed



TREATMENT

Members found they needed to try many treatment options before finding the right combination

Common treatment discussions included opioids, enzyme treatments, alternative medicine, other medications, diabetes management, and dietary changes

Some members found non-traditional treatment options to be most effective

LIMITATIONS



Some **important themes may have been missed in this thematic analysis** if not initially identified as part of the theoretical framework



The community is ongoing, and **additional insights or variations in themes are likely to emerge with repeated thematic analysis**



Only individuals comfortable discussing their health condition online contributed insights

CONCLUSIONS



This observational analysis of patient experiences of CP with EPI using a patient-driven online community **determined that key areas of focus were pain, diagnosis, treatment, and diet**



Results highlight areas for practitioners to focus patient education to **optimize experiences, care, and QoL of patients** with CP with EPI



Ongoing analysis of community discussions and comparisons of findings to registry data is practical/novel and will **help develop a comprehensive understanding of the patient's lived experience with CP with EPI**

- Participation in the online patient community is currently available and open to all

Reference

1. Diéguez-Castillo C, et al. *Medicina (Kaunas)*. 2020;56(10):523.

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