Neuropsychiatric Comorbidities Self-reported by Interstitial Cystitis Patients on an Online Peer Health Network

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Introduction

INTRODUCTION

Studies have found high prevalence rates of depression and anxiety in Interstitial cystitis (IC) cohorts, and research suggests these comorbidities exacerbate IC/BPS symptoms. So far, the research conducted on neuropsychiatric comorbidities has been limited to small numbers of samples. Big data through online platforms can help us with comorbidity mapping.

Specifically, we hypothesized that IC patients have a higher probability of reporting anxiety and depression as comorbidities than other patient groups on an online peer health network.

Inspire, a digital peer health platform, has over 200 communities and 2 million members. **Over 21,000 patients on Inspire list having IC as a condition.**

The average number of characters per post on Inspire (1,695) is over 16 times that of the median post length on Facebook (103), and almost 11 times the average post on Google+ (156). Over 1.5 billion words have been written on Inspire, making it the largest repository of English-language patient-created content about diseases on the Internet.

Objectives & Methods

OBJECTIVES

- To determine self-reporting rates of neuropsychiatric phenotypes in a large online community of IC patients
- To determine whether using social media networks to capture the patient and caregiver voice from user-generated content provides important insights for disease research.

METHODS

To test our hypotheses, we compared the rates of selected neuropsychiatric disorders in patients who listed IC as a condition against the rates in patients who listed any health condition besides IC. Fischer exact tests were performed to compare groups.

Table 1: Comparison of neuropsychiatric phenotypes

% with IC vs % without IC	P value (Fisher exact test)
Depression (15.8% vs 14.2%)	0.0017
Anxiety (3.4% vs. 1.2%)	< 0.00001
Migraine (1.3% vs 0.6%)	< 0.00001
Obsessive Compulsive Disorder (0.2% vs 0.1%)	0.0075

Results

- Our preliminary analysis of Inspire member profiles confirms previous studies' findings (1,2) of high rates of depression and anxiety with IC/BPS (15.8%) when compared to other patient groups. This is greater than the overall active Inspire patient population who listed any condition (other than IC) and also listed depression (14.2%) as compared by Fisher Exact Test (controlled for multiple testing. p < 0.00001).
- Anxiety is also more frequently declared by Inspire members with IC (2.4%) than those without IC (1.2%, p < 0.00001).
- This analysis also found that Inspire members who chose to self-report diagnoses on their profiles additionally reported more comorbidities of migraines, PTSD, and sexual assault than other patient groups, as published literature has also found (3,4).
- In contrast, the IC population does not differ from the rest of Inspire in listing bipolar disorder (2.4% vs 2.7%, p =0.115).
- To ensure that IC/BPS patients on Inspire do not generally have higher rates of all comorbidities, we also compared rates of eczema and hepatitis, which were not significant.

Discussion

Our neuropsychiatric comorbidity mapping confirms previous studies' findings of high rates of depression and anxiety with IC. To our knowledge, no study has yet reported that OCD might be more common in this patient population, which our preliminary analysis of member profiles suggests.

Since the usage of online platforms for epidemiological purposes is relatively new, we need a better understanding of a) how patients who join these digital communities differ from those who do not and b) how patients who report diagnoses on their profiles differ from those who do not. We aim to conduct follow-up surveys with Inspire and other demographically distinct IC cohorts to assess replicability of findings and obtain more details.

References & Acknowledgements

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