Evaluating Patient-Reported Experience along the Inflammatory Bowel Disease Patient Journey in Portugal

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INTRODUCTION

Inflammatory Bowel Disease (IBD) represents a chronic imuno-mediated disorder of the gastrointestinal tract, mainly divided in Chron's Disease and Ulcerative Colitis. Epidemiological estimates indicate a high prevalence in Portugal, with an estimated ~38 thousand patients in 2022. [1] A recent national study revealed, in a societal perspective, the high burden and cost associated with IBD. [2] Nevertheless, patient experiences and unmet needs faced throughout the IBD patient journey remain to be elucidated.

OBJECTIVE

Characterize the IBD patient journey in Portugal, through the patient-reported experiences and unmet needs, from symptom onset to diagnosis, treatment, and follow-up.

METHODS

Based on a targeted literature review, an exploratory sequential mixed methods design was used to characterize the IBD patient journey in Portugal – **1st symptoms**, **1st appointment**, **diagnosis**, **treatment** and **follow-up**. This method involves the integration of qualitative and quantitative results, to provide a better understanding of the research problem.

1. QUALITATIVE PHASE

The qualitative phase consisted of 9 semi-structured interviews with IBD patients (Crohn's disease (n=7); Ulcerative Colitis (n=2))**.** A "building" approach was used to develop the quantitative survey items based on the qualitative findings. A qualitative script with open-ended questions was prepared to support the interviews, focusing on patient experiences, unmet needs and impact felt throughout each journey stage. The interviews were conducted by two trained interviewers.

2. QUANTITATIVE PHASE

The quantitative phase consisted of an online survey targeting the Portuguese IBD patient population. The objective of the survey was to quantify the previously collected information in the qualitative phase. **Data collection** period lasted **1 month** (from February to March 2022), during which members from two national patient associations (APDI - *Associação Portuguesa da Doença Inflamatória do Intestino* and *Crohn e Colite Portugal*) answered the questionnaire. The anonymized data was self-reported and collected through an online platform (Qualtrics). **A descriptive analysis of the quantitative survey data is presented below**.

RESULTS

406 IBD patients (62% Crohn's disease; 38% Ulcerative colitis) answered the survey. The **average age of participants was 37** (SD=11,6) **years** and 58% were in the 17-39 age group. 74% of the participants were female. The geographical distribution of participants covered all 18 districts of mainland Portugal and islands. **61%** and **19%** of participants reported **moderate to severe and mild disease severity**, respectively. The average disease duration (calculated as the difference between current age and age at symptom onset) was 12 (SD=10,2) years. 54% of the participants reported having a health insurance/subsystem and **the majority were of working age**, with 76% reporting as being employed.

1st Symptoms

Average age at symptom onset was 25 (SD = 10,6) years of age, with 38% of IBD patients reporting symptoms to be **very** to **extremely limiting** in their daily life activities. (Figure 1)

Figure 1. Limitations in patient's daily life activities caused by IBD symptom onset

1st appointment

On symptom onset, 5% of IBD patients reported that they didn't seek help or information from people/health professionals, primarily due to **devaluation of the importance of symptoms** and **lack of understanding of their health condition**.

The majority of participants reported resorting to the public sector for the first appointment (65%), mainly to a general practitioner (GP) (33%). In the private sector (35%), Gastroenterology was the main medical specialty. Nonetheless, **28%** of IBD patients reported a period of **more than 6-months** between **symptom onset** and resorting to the **first healthcare appointment.** (Figure 2)

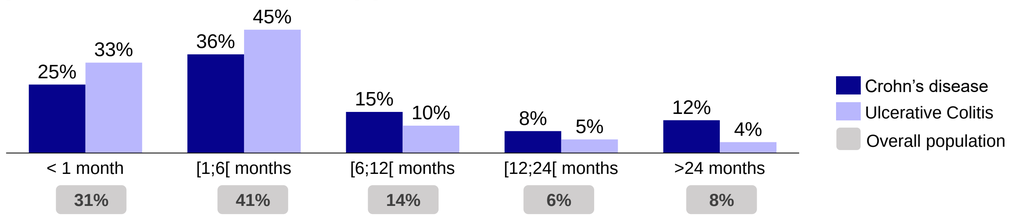

Figure 2. Time between IBD symptom onset and 1st appointment

Diagnosis

The majority of responders (63%) reported being diagnosed in the **public sector**, of which **89% by a gastroenterologist, after GP referral**.

38% of IBD patients reported a period of more than 1-year until definitive diagnosis. (Figure 3)

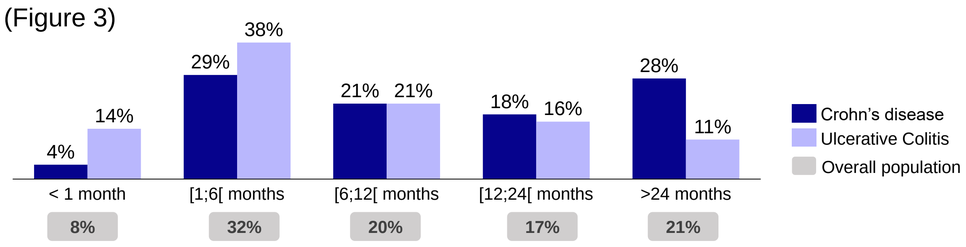

Figure 3. Time between 1st appointment and IBD definitive diagnosis

Patients shared their expectations of having a timely and precise diagnosis, while receiving the adequate information at the moment of diagnosis. However, **49%** considered **initial symptoms were devalued by physicians**, **43%** reported initial **misdiagnosis** and **46%** reported not **receiving all the relevant information about the disease at the moment of diagnosis**.

Treatment

48% of patients reported being on biologics and 41% on conventional therapy. There were notorious differences in current treatment between Ulcerative Colitis and Crohn's disease patient subgroups. (Figure 4)

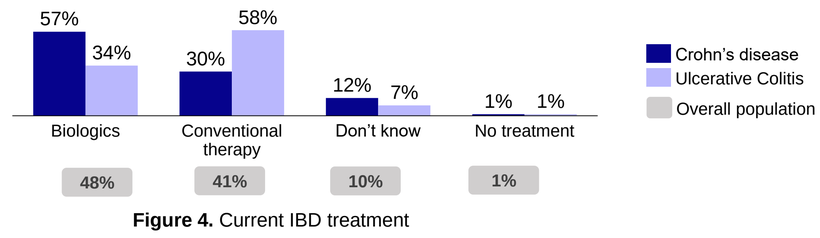

Figure 4. Current IBD treatment

70% of patients currently on biologics only started treatment after failing more than one line of conventional therapies. (Figure 5)

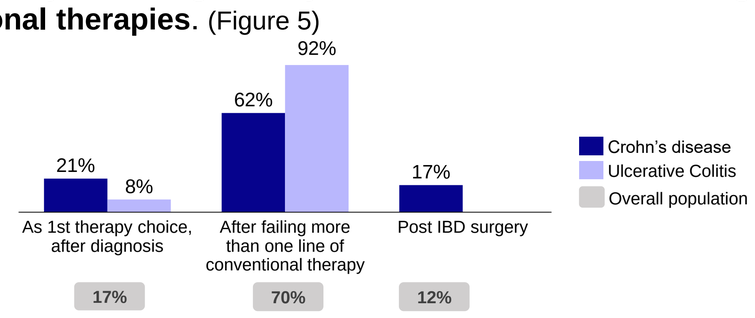

Figure 5. Timing of biologic treatment initiation

18% of patients on biologics reported delays in treatment initiation mainly due to hospital approval (29%), self-doubt regarding biologics efficacy/safety (17%) and COVID 19 pandemic period (14%).

Regarding biologics administration, **64%** of patients reported **administration at hospital level**, with a direct impact on **work absenteeism**, with **77% reporting missing part or a whole workday during treatment days.**

15% of IBD patients indicated not being involved in treatment decision-making

Follow-up

33% of IBD patients reported having multidisciplinary care at the main hospital of follow-up. Nevertheless, **54% had to resort, at their own cost, to additional medical care outside of their main healthcare institution**.

Healthcare most frequently sought by IBD patients were **nutrition** (17%), **dermatology** (16%), and **psychology** (15%).

38% reported **gaps in integrated care** between healthcare specialties at the main institution of follow-up

13% reported they **couldn't seek follow-up care with other specialties due to financial constraints**

22% of IBD patients reported that they don't have all the necessary knowledge and tools to manage their disease

CONCLUSIONS

IBD patients in Portugal face **several barriers along their patient journey**. **Gaps in IBD awareness among the overall population, patients and GP,** translate **in delays in early diagnosis, access to early treatment** and **gaps in multidisciplinary integrated follow-up care**. Study results highlight current unmet needs and can support future patient-centered initiatives, focused on optimizing patient access to healthcare and treatment.

References

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