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Inflammatory Bowel Diseases (IBDs) *vs* Irritable Bowel Syndrome (IBS): A comparative qualitative study on prevalent themes, emotions and Quality of Life (QoL)

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Abstract

Introduction: Inflammatory bowel diseases (IBDs) (including Crohn's disease, Ulcerative colitis) and Irritable Bowel Syndrome (IBS) are different debilitating conditions affecting the digestive system. Both diseases significantly impact patients' lives, not only physically but also psychologically. Although some comparative literature exists, there is currently a lack of studies exploring qualitative differences in how pathology is experienced. In the present study, we explore the broad spectrum of psychological impacts caused by gastrointestinal disorders, including the experience of surgical interventions on the intestines, impact of the disease activity, severity of symptoms, and Quality of Life (QoL). Additionally, we examine how the diagnosis can be perceived as an emotional trauma for patients.

Methods: A total of 366 participants was enrolled (aged between 18 and 65 years, Mage=37.06, SD=12.09), 82% of whom are female. Patients were divided into 4 subgroups and compared according to the gastrointestinal pathology: (1) Crohn's disease (IBD); (2) Ulcerative colitis (IBD); (3) Irritable Bowel Syndrome (IBS); (4) Other condition / Subject awaiting diagnosis. From these participants, we obtained 87 descriptive texts (1668 words; 104 segments) about describing the pathological condition, emotional experiences, and experiential aspects related. The software MAXQDA Analytics Pro (v. 22.7.0) was employed for the textual analysis of prevalent themes associated with each specific medical condition.

Results: Statistically significant differences were found among the four intestinal condition groups in both perceived quality of life ($\chi^2 = 19.12$, $p = 0.0003$) and diagnosis experience ($\chi^2 = 21.57$, $p = 0.043$), worse for IBD group, suggesting that the perception of the impact of the intestinal condition varies depending on the diagnosis. The qualitative analyses highlighted emotional, psychological, and social aspects, including anxiety, depression, guilt, and social isolation, which significantly impacted the patients' daily lives.

Discussion: Previous research has primarily compared QoL across gastrointestinal conditions without delineating the distinct sources of suffering characterizing each disorder. The identification of significant differences in patient experiences and underlying themes supports a more precise and condition-specific personalization of therapeutic strategies and clinical management, emphasizing the necessity of adapting interventions to the unique clinical profiles of each patient population.

Take-home message: A detailed analysis of the distinct experiential and thematic differences across gastrointestinal conditions provides a methodological foundation for developing more tailored therapeutic interventions, emphasizing the importance of integrating condition-specific patient experiences into clinical decision-making and treatment planning.

Key words: Comparative study; IBD; IBS; QoL; qualitative study.

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INTRODUCTION

Clinical and psychological features of IBD

Inflammatory Bowel Diseases (IBD) are chronic and complex conditions, characterized by persistent inflammation of gastrointestinal tract. These disorders are often associated with painful and debilitating symptoms that significantly impact patients' QoL (QoL) [1]. A growing body of literature highlights the psychological burden experienced by individuals with IBD, including anxiety, depression, and stress [2-4]. The unpredictable nature of the disease, the fear of relapses, and the ongoing challenges of disease management contribute to this psychological distress [5].

Anxiety is a prevalent concern among IBD patients, especially during periods of disease exacerbation [6]. Anticipation of symptoms such as pain, diarrhea, or fatigue can lead to heightened vigilance and chronic apprehension. Anxiety may also experience anxiety related to treatment, potential side effects of medications, and the possibility of surgical interventions. Notably, anxiety has been associated with poor sleep quality, which may further impair both physical and mental well-being [7].

Depression is another common psychological challenge among IBD patients [8]. The chronic and often unpredictable progression of the disease can lead to feelings of helplessness and a diminished sense of control [9]. As noted by de Castro Humes & Fráguas [10], the ongoing loss of autonomy over one's health can lead to emotional disengagement, sadness and apathy. Chavarría and colleagues [11] further emphasize that the debilitating physical burden due (i.e. chronic fatigue) to these medical conditions can exacerbate depressive symptoms. Importantly, depression symptoms may also compromise a patient's ability to effectively manage their condition effectively, potentially leading to worse health outcomes [12].

Stress plays a significant role in the IBD experience [13]. Daily disease management often demands careful dietary planning, monitoring symptoms, and managing emotional triggers, each of which can be inherently stressful [14]. Moreover, stress itself can negatively affect gut function, potentially triggering or intensifying IBD symptoms. This bidirectional relationship creates a vicious cycle that complicates disease management and increases psychological vulnerability [15]. Indeed, as noted by Mikocka-Walus et al. [16], 'antidepressants may not only alleviate depressive symptoms but also exert anti-inflammatory effects, thereby potentially reducing IBD activity'.

IBD progresses through distinct stages, which can vary across individuals but generally follow a recognizable pattern. Understanding these stages is essential for effective disease management and for addressing the psychological impact that often accompany each stage.

In the early stage, IBD may present with mild or intermittent symptoms, such as abdominal pain, occasional diarrhea or general gastrointestinal disturbances. As the disease advances, it can enter an active inflammatory phase characterized by more severe manifestations, including frequent diarrhea, rectal bleeding, fever, and weight loss. During this stage, patients often require intensive treatment, including pharmacological interventions and, in some cases, surgical procedures

In some cases, IBD can enter a phase of remission, during which symptoms diminish or disappear entirely. Although remission brings physical relief, many patients continue to experience anxiety and fear about potential disease [17].

The severity of IBD symptoms varies widely between individuals and across different phases of the disease. While some patients may experience mild and occasional symptoms, others endure severe and debilitating manifestations. The intensity of symptoms significantly influences the patient’s psychological well-being. Those with severe symptoms often face chronic anxiety and stress due to relentless burden of pain and physical discomfort. Additionally, factors such as significant weight loss and intestinal dysfunction can negatively impact body image and self-esteem. However, even patients with milder symptoms may experience psychological distress and uncertainty regarding the progression of the disease. Ongoing disease management requires continuous vigilance, regardless of current symptom severity [18].

In some cases, surgical intervention becomes necessary. Intestinal surgeries are often necessary for patients with IBD, especially when symptoms become severe or do not respond adequately to medical therapies. These interventions can involve the removal of parts of the intestine affected by inflammation or the creation of stomas, which allow the passage of feces through a surgically created opening in the abdomen. Although these interventions can be lifesaving and improve QoL, they can also have a significant psychological impact on patients [19].

The prospect of intestinal surgery itself can cause considerable anxiety and fear in patients. Patients may worry about surgical risks, postoperative complications, and long-term health consequences. The presence of a stoma can be particularly stressful, as it implies a significant alteration in the patient's lifestyle and body image.

Clinical and psychological features of IBS

On the other hand, irritable bowel syndrome (IBS) is a functional gastrointestinal disorder primarily characterized by symptoms such as abdominal pain associated with changes in stool form or frequency. This condition affects between 5% and 10% of otherwise healthy individuals at any given time and typically follows a pattern of relapse and remission. The most well-known risk factor is acute enteric infection, but IBS is also more prevalent in individuals with psychological comorbidities and among young adult women compared to the general population. The pathophysiology of IBS is not fully understood, but it is well established that there is disrupted communication between the gut and the brain, leading to motility disturbances, visceral hypersensitivity, and altered CNS processing. Other less consistent mechanisms may include genetic associations, changes in the gastrointestinal microbiota, and disruptions in mucosal and immune function. To effectively manage symptoms, it is important to crucial to improve doctor-patient relationship through trust and empathetic communication, fostering a welcoming environment to promote education and psychoeducation about the condition, and thus enact dietary changes and reduce the need to rescue therapies with antispasmodic drugs [20-22].

Although there are numerous studies that demonstrate patients' needs or the impact of trauma on patients' QoL and the development of psychopathologies and therefore the significance of the mind-body connection in IBS [23-25], no study correlates this gastrointestinal condition with others.

Literature comparison between IBD and IBS

A number of comparative studies have explored how IBD and IBS affect health-related QoL (HRQoL), psychological well-being, and the role of psychosocial factors in disease severity.

For instance, Frank et al. [26] investigated how irritable bowel syndrome (IBS) affects HRQoL by comparing SF-36 scores from IBS patients with US population norms and patients with other chronic disorders. They analyzed two IBS groups (one from an HMO and one from clinics and the community) and found that IBS patients had significantly lower HRQoL scores compared to the general US population, as well as compared to patients with GERD, asthma, and migraine. Compared to patients with panic disorders and rheumatoid arthritis, IBS patients showed better HRQoL scores. Overall, the study highlights that IBS is associated with substantial impairment in QoL, although less severe than in some other chronic conditions.

Blagden et al. [27] conducted a comparative study to examine the impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) on health-related QoL (HRQoL). Although IBD involves more severe physical symptoms and treatment burdens, the study found that HRQoL was significantly lower in IBS patients. The key difference lay in how the conditions affected QoL: individuals with IBS experienced greater impairments in social and emotional functioning, whereas IBD was more associated with physical symptom severity. The findings underscore the importance of tailored support by gastroenterology nurse specialists, particularly for the psychological and social challenges faced by IBS patients.

Pace et al. [28] compared the impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) on HRQoL, psychological distress, and perceived burden of stressful life events in an outpatient sample. Using the SF-36, SCL-90, and Holmes & Rahe scales, they found that HRQoL was similarly reduced in both IBS and IBD patients compared to the general Italian population, and psychological symptom severity did not differ significantly between the groups. However, IBS patients reported a significantly higher burden of recent stressful life events. The study challenges traditional distinctions between "organic" and "functional" illnesses by showing that IBS patients experience levels of distress and impairment comparable to those with IBD.

Tkalčić et al. [29] investigated differences between irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) patients in health-related HRQoL, affective status, personality traits, and stressful life events. They found that IBS patients reported better physical HRQoL but had significantly higher anxiety and neuroticism levels compared to IBD patients. Furthermore, neuroticism emerged as a strong predictor of perceived disease activity in IBS. The study concludes that IBS patients are more sensitive to psychosocial factors influencing their gastrointestinal symptoms, highlighting the psychological dimension of IBS in contrast to the more organic nature of IBD.

Finally, Geng et al. [30] conducted a meta-analysis to compare the prevalence and severity of comorbid depression between patients with irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD). Analyzing data from 22 studies with over 2,000 participants, they found that while the overall prevalence of depression did not significantly differ between IBS and IBD patients, those with

IBS experienced more severe depression and anxiety symptoms. Most of the included studies were rated as high quality. The authors conclude that both disorders require careful assessment and management of psychological symptoms, with particular attention to the higher severity seen in IBS patients.

Table 1 shows a comparative overview of key findings from several studies examining the impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) on HRQoL, psychological distress, and psychosocial factors. These studies highlight differences in the severity of physical symptoms, psychological distress, and social and emotional functioning between IBS and IBD patients, underscoring the importance of considering both the differences in physical and psychological aspects when addressing these conditions.

Table 1. Comparative overview of health-related QoL and psychological distress in IBS and IBD patients.

Variables compared	IBD	IBS
Health-Related QoL (HRQoL)	HRQoL similarly reduced compared to the general population, but more severely affected by physical symptoms (Blagden et al., 2015; Pace et al., 2009).	Significantly lower HRQoL compared to the general population, worse than GERD, asthma, and migraine, but better than panic disorder and rheumatoid arthritis (Frank et al., 2002).
Depression Prevalence	Similar depression prevalence as IBS, but less severe symptoms compared to IBS (Geng et al., 2018).	Similar prevalence compared to IBD, but more severe depression and anxiety (Geng et al., 2018).
Anxiety	Lower levels of anxiety compared to IBS patients (Tkalčić et al., 2010).	Higher levels of anxiety compared to IBD patients, along with higher neuroticism (Tkalčić et al., 2010).
Psychological Profile	Psychological distress similar to IBS, but less influenced by psychosocial factors (Pace et al., 2009; Tkalčić et al., 2010).	Higher neuroticism and psychological distress, with greater vulnerability to psychosocial factors influencing symptoms (Tkalčić et al., 2010).
Impact of Stressful Life Events	Perceived burden of stressful life events lower compared to IBS patients (Pace et al., 2009).	Higher perceived burden of recent stressful life events (Pace et al., 2009).
Social and Emotional Impact	More physically debilitating, with less impact on social and emotional aspects compared to IBS (Blagden et al., 2015).	Greater impairment in social and emotional aspects of life (Blagden et al., 2015).

Physical Symptoms	Severe physical symptoms and treatment burdens (Blagden et al., 2015).	Mild to moderate physical symptoms (Pace et al., 2009; Blagden et al., 2015).

Present study aims

Given these premises, the aim of the present study aims to compare prevalent themes, emotional patterns, and QoL among individuals with structural gastrointestinal disorders and those with functional gastrointestinal disorders. By examining these dimensions, the study seeks to uncover meaningful differences and similarities that may guide more effective patient care, inform tailored psychological and medical interventions, and enhance overall management strategies in both disorders.

In particular, the present study aims to examine psychological patterns, similarities and differences between patients suffering from IBD, IBS or patients with gastrointestinal conditions awaiting diagnosis.

METHODS

Study design and procedure

The present study employed a mixed-methods design combining quantitative demographic data with qualitative textual analysis. Participants were recruited through online platforms, including social media groups coordinated by ambassadors and patient members of AMICI-ONLUS, as well as through direct outreach at the University of Messina. Informed consent was obtained from all subjects involved in the study. All data were anonymized and handled in accordance with ethical guidelines After approval from the Ethics Committee at the IRB of the Polish Society of Disaster Medicine (Approval Date: January 3, 2023; Approval No. 15.01.2023.IRB) data collection took place from February 13th, 2023, to March 23rd, 2023. The tool utilized was a Google Form® containing the anagraphical sheet and a medical history questionnaire to assess specific sub-sample characteristics and experiences (See Table 2).

Table 2. Medical history questionnaire.

Questions	Answer
Do you suffer from IBD (Inflammatory Bowel Disease)?	Yes, I suffer from Crohn's Disease / Yes, I suffer from Ulcerative Colitis / No, I suffer from Irritable Bowel Syndrome / No, I do not suffer from any intestinal disease
At what age did the disease first manifest?	Number
Have you undergone intestinal surgery?	Yes / Yes, I have had a stoma / Yes, I currently have a stoma / No, I have not had any surgeries
At present, what is the nature of the condition?	Active / In remission
How severe are your symptoms?	Absent/ Mild / Moderate / Severe
Do you believe that your IBD/IBS negatively impacts your QoL?	Not at all / A little / Moderately / A lot / Extremely
Was discovering you had IBD/IBS traumatic for you?	Not at all / A little / Moderately / A lot / Extremely
Describe your experience in dealing with the pathology by providing a brief text	Open-ended response

Data analysis

The statistical analysis was conducted using Microsoft Excel, which proved to be a versatile tool for data coding, frequency calculations, and percentage computations. Excel allowed for efficient data organization and summarization, enabling us to gain valuable insights into the quantitative aspects of the study. Additionally, MAXQDA Analytics Pro 2022 (v. 22.7.0) was employed for the textual analysis of prevalent themes associated with each specific medical condition. MAXQDA facilitated the qualitative analysis by assisting in the identification of recurring patterns, sentiments, and themes within the textual data.

The open-ended question reported here as "themes" has been summarized through a qualitative analysis procedure. This method aims to provide a qualitative approach close to the experiences of affected people, challenging the distances and size of a real sample and overcoming the limits of quantitative research (See: Lappeman et al. [31]).

Thematic prevalence analysis

In the present study, the method of thematic prevalence analysis was used to identify and examine recurring themes or patterns within textual data. The process began with the collection of relevant materials, such as transcripts and written responses. Once the data was gathered, it was divided into meaningful segments, such as sentences, phrases, or paragraphs—that represent distinct ideas or concepts.

Each segment was then labelled with a code corresponding to a specific theme or concept. These codes were either predefined based on the research questions or emerged inductively as the analysis progressed. Similar codes were subsequently grouped together into broader categories, representing the key themes that appeared frequently across the data.

The prevalence of each theme was measured by counting how often it occurred within the dataset. This frequency helped determine which themes were most prominent and significant. Finally, the themes and their prevalence were interpreted in relation to the research objectives, providing insights into the underlying patterns or trends present in the data.

RESULTS

Study participants

The sample of the study consists of a total of 336 participants (aged between 18 and 65 years, mean age = 37.06, SD = 12.09), comprising: (1) 111 individuals affected by Crohn's Disease (IBD); (2) 180 individuals with Ulcerative Colitis (IBD); (3) 34 individuals with Irritable Bowel Syndrome (IBS); (4) 11 participants report various conditions or illnesses but have not yet received a diagnosis (Awaiting diagnosis / Other condition). From these participants, we obtained 87 text (1668 words; 104 segments) describing the pathological condition, emotional experiences, and experiential aspects related to IBD.

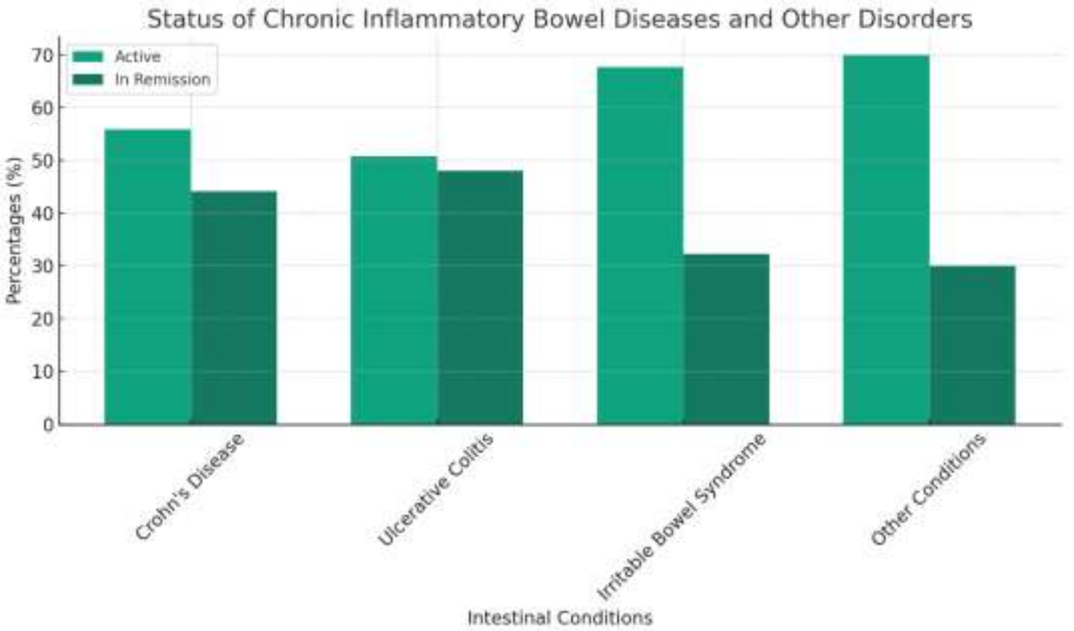
The sample is skewed towards females, who constitute a significant 82.4% of the sample, compared to 17.6% males. Geographically, the sample is varied, with the largest portion (37.5%) from the North region, followed by 28.6% from the South, 17.9% from the Centre, and 16.1% from the Islands. The sample is educationally diverse, with the majority (48.8%) having completed upper secondary education. Those with a degree represent 20.8%, while postgraduate qualifications are held by 17.0%. A smaller segment has lower educational attainment, with 8.0% having completed lower secondary education and a mere 0.3% with just elementary education. Reflecting a range of economic and social positions, 35.1% of the sample are employees, 21.1% are students, 11.9% are freelancers, another 11.9% are housewives, 9.5% are workers, and 1.5% are retirees. In terms of marital status, singles account for 32.7% of the sample, closely followed by married individuals at 39.9%. Those cohabiting are 22.3%, while separated and divorced individuals each make up 2.4%, and widows are the smallest group at 0.3%.

Clinical features

Stages of the disease

The bar chart 1 provides a clear and immediate snapshot of the status of various diseases: (1) Crohn’s disease (IBD); (2) ulcerative colitis (IBD); (3) irritable bowel syndrome (IBS); and (4) other intestinal disorders (subjects awaiting diagnosis). Each condition is represented with two bars: one for the percentage of patients in an active phase and the other for those in remission.

Figure 1. Status of chronic inflammatory bowel diseases and other disorders.



In the case of Crohn's Disease, it is observed that the majority of patients (about 56%) are currently in an active phase of the disease, while 44% are in remission. This indicates that more than half of the patients with Crohn's Disease are experiencing symptoms of the disease.

For Ulcerative Colitis, the distribution is almost balanced between patients in the active phase (about 51%) and those in remission (about 48%), with a small percentage falling into other categories. This suggests a slight prevalence of active disease phases among patients with Ulcerative Colitis.

For patients with IBS, the majority (about 68%) are in an active phase, while about a third are in remission. This indicates that IBS is predominantly an active symptomatic phase among patients.

Finally, for patients classified as "other" (indetermined colitis/awaiting diagnosis) about 70% are in an active phase of their intestinal condition, while 30% are in remission. This group may include a variety of less common intestinal conditions.

Severity of symptoms

Table 3 above illustrates the severity of symptoms for various intestinal conditions such as Crohn's Disease, Ulcerative Colitis, Irritable Bowel Syndrome, and other intestinal conditions. The severity is categorized into four levels: absent, mild, moderate, and severe. This chart provides a clear visual representation of how these conditions impact patients in terms of symptom severity.

Table 3. Severity of symptoms for various intestinal conditions.

Intestinal Conditions	**Absent Symptoms (%)**	**Mild Symptoms (%)**	**Moderate Symptoms (%)**	**Severe Symptoms (%)**
Crohn's Disease (N=111)	17.1	29.7	39.6	13.5
Ulcerative Colitis (RCU) (N=180)	18.3	25.0	42.8	13.9
Irritable Bowel Syndrome (IBS) (N=34)	3.1	43.8	50.0	3.1
Other conditions (N=11)	10.0	20.0	70.0	0.0

For Crohn's Disease, a significant proportion of patients experience moderate symptoms (39.6%), followed by mild symptoms (29.7%). Interestingly, a smaller yet notable percentage of patients (13.5%) suffer from severe symptoms, and a similar proportion (17.1%) exhibit no symptoms at all. This suggests a broad spectrum of symptom severity among patients with Crohn's Disease, indicating varied impacts on their QoL.

In the case of Ulcerative Colitis, the distribution is somewhat similar to Crohn's Disease, with a substantial number of patients experiencing moderate symptoms (42.8%). Mild and severe symptoms are relatively evenly distributed (25% and 13.9% respectively), and a slightly lower percentage of patients (18.3%) report no symptoms. This pattern underscores the fluctuating nature of Ulcerative Colitis, where patients may experience varying degrees of symptom severity.

For patients with IBS, the majority experience moderate (50%) to mild (43.8%) symptoms, with a very small percentage suffering from severe symptoms (3.1%). Only a minimal number of patients (3.1%) report no symptoms. The prevalence of moderate to mild symptoms suggests that while IBS may not often be severely debilitating, it consistently affects the daily lives of most patients.

Lastly, for other intestinal conditions, the majority of patients (70%) experience moderate symptoms, followed by a smaller proportion with mild symptoms (20%). Notably, none of the patients in this category report severe symptoms, and a small percentage (10%) report no symptoms. This indicates that while these conditions are generally not as severe as others, they still significantly affect a majority of the patients.

Surgical interventions

Table 4 summarizes the percentages of patients, divided by intestinal condition, who have undergone surgery, have had a stoma, currently have a stoma, and did not undergo surgery. It's useful for getting an immediate idea of the impact of these conditions on the need for surgical treatments and the use of stomas.

Table 4. Impact of IBD on the need for surgical treatments and the use of stomas.

Intestinal Conditions	**Underwent Surgery (%)**	**Had a Stoma (%)**	**Currently Have a Stoma (%)**	**Did Not Undergo Surgery (%)**
Crohn's Disease (N=111)	28.8	2.7	2.7	65.8
Ulcerative Colitis (RCU) (N=180)	2.2	2.8	2.8	92.2
Irritable Bowel Syndrome (IBS) (N=34)	3.0	6.1	0.0	90.9
Other conditions (N=11)	11.1	0.0	0.0	88.9

In the group affected by Crohn's Disease, about 29% of patients have undergone intestinal surgery, with a small percentage of these (about 3%) currently having a stoma, and a similar percentage having had a stoma in the past. However, the majority, about 66%, have not needed surgical interventions.

In the case of Ulcerative Colitis, the percentage of patients who have undergone surgery is significantly lower, with only 2.2% currently having a stoma and 5.6% having had a stoma in the past. The vast majority, over 91%, did not need surgical interventions.

For patients with IBS, the need for surgical interventions is even lower. Only a small number of patients (about 3%) required surgery, and a slightly higher percentage have had or have a stoma.

Finally, in the group suffering from other intestinal conditions, only 11.1% have undergone surgical procedures, while the majority (about 89%) have not needed such procedures.

Impact on QoL

The following Table 5 provides a clear view of how patients with different intestinal conditions perceive the impact of their disease on their QoL, ranging from no impact to a very significant impact.

Starting with Crohn's disease, a small fraction of patients (1.8%) believe their condition doesn't affect their QoL at all, suggesting that they might be in remission or have mild symptoms. However, the story changes as 13.5% of patients report only a minor impact, possibly indicating manageable symptoms. The largest group, nearly half of the patients (46.8%), feels a moderate impact, which may reflect a significant but bearable interference in daily life. The narrative takes a more serious turn as 19.8% of patients report a major impact, and a considerable 18% experience an extremely high impact, indicating severe challenges and possibly frequent flare-ups that drastically affect their daily functioning and well-being.

For Ulcerative Colitis (RCU), a very small percentage of patients (0.6%) report no impact, hinting at effective management or mild disease progression. However, a notable 14.4% experience a mild impact, and half of the patients (50%) feel a moderate impact, suggesting that while the condition is manageable for many, it still poses significant challenges. The story deepens as 17.8% of patients report a considerable impact, and a similar proportion (17.2%) faces an extremely high impact, underlining the severity of this condition in a significant portion of patients.

In the case of IBS, the narrative is slightly different. A small group (3.1%) perceives no impact, possibly due to mild or infrequent symptoms. However, a larger 40.6% report a slight impact, and about a third (31.3%) experience a moderate impact, reflecting the condition's pervasive but often manageable nature. The story takes a serious turn for 9.4% who face a significant impact, and for 15.6% who endure a very high impact, revealing that for a significant minority, IBS can be a debilitating condition.

Lastly, for other intestinal conditions, the narrative is varied. A notable proportion experiences a mild to moderate impact (33.3% each), while 22.2% report a significant impact, and 11.1% face an extremely high impact. This suggests a range of experiences, potentially reflecting a variety of less common intestinal disorders with varying symptoms and impacts on QoL.

Diagnosis as a traumatic experience

The Table 6 breaks down the responses into categories ranging from "Not Traumatic" to "Extremely Traumatic". It reveals that while a small percentage of patients did not find the diagnosis traumatic, a significant proportion experienced varying degrees of trauma. In conditions like Crohn's disease and ulcerative colitis, a notable number of patients found the discovery to be very or extremely traumatic, highlighting the profound emotional impact such diagnoses can have. Even in cases of IBS other conditions, there's a clear indication of the diagnosis being moderately to extremely traumatic for a substantial number of patients.

A clear picture emerges regarding the differences in emotional impact of the diagnosis and the perceived QoL among the various intestinal conditions.

Regarding the impact of the disease on QoL, both Crohn's disease and ulcerative colitis (UC) show extremely high percentages of patients reporting a significant impact: 84.6% for Crohn's and 85% for UC (combining the responses "enough," "a lot," and "very much"). This indicates that the vast majority of patients suffering from these two forms of IBD experience a strongly compromised QoL. In comparison, patients with IBS report a significantly lower impact: only 56.3% perceive a considerable influence on their QoL. Those suffering from "other intestinal conditions" fall into an intermediate position, with 66.6% reporting a negative perception, suggesting that although the disorder is present, its impact does not reach the devastating levels of IBDs.

As for the perceived trauma at the time of diagnosis, Crohn's and UC again show very high percentages: 80.1% of Crohn's patients and 84.9% of UC patients consider the diagnosis to have been moderately to extremely traumatic. These figures reflect not only the intrinsic severity of the disease but also the emotional burden associated with the awareness of having to live with a chronic and disabling condition. Conversely, IBS shows only 31.3% of patients reporting a moderate or severe level of trauma, while a large majority (68.8%) perceive the diagnosis as little or not at all traumatic, probably because the disease, while bothersome, is seen as less severe or threatening. For other intestinal conditions, about 44.4% report a moderate trauma, indicating a variability probably linked to the heterogeneous nature of these disorders.

Chi-Square test results on perceived quality of life and diagnosis experience

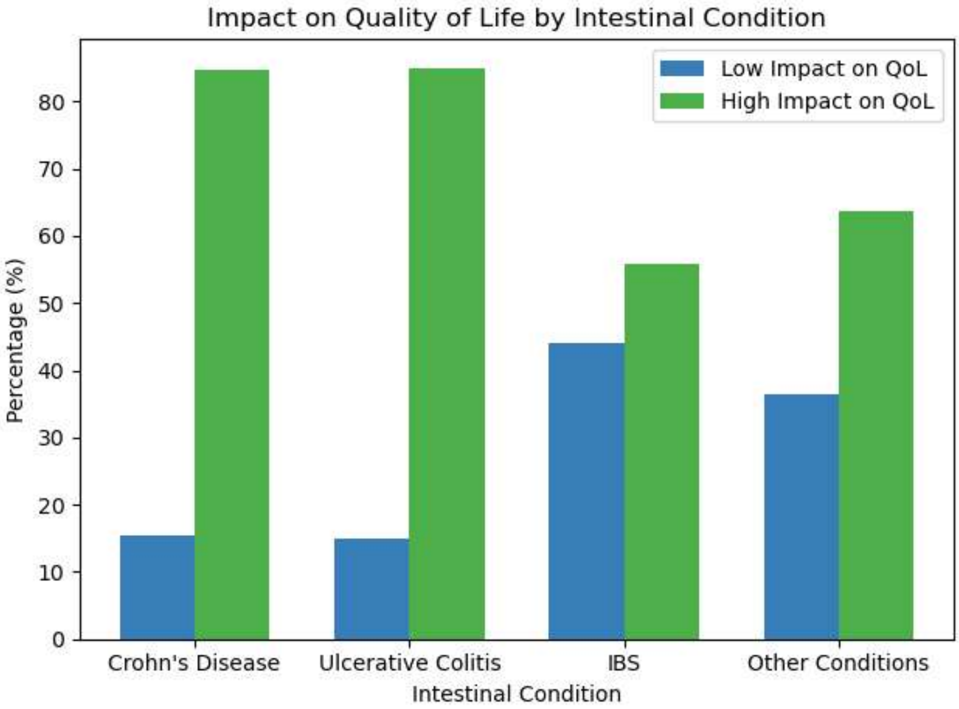
The Chi-square test for perceived quality of life yielded a value of $\chi^2 = 19.12$ with 3 degrees of freedom and a p-value = 0.0003. This result indicates a statistically significant difference in the distribution of perceived quality of life (low vs. high impact) among the four intestinal condition groups.

Table 5. Perceived impact on QoL.

Intestinal Condition	**Low Impact on QoL (%)**	**High Impact on QoL (%)**	**p-value**
Crohn's disease (N=111)	15.3%	**84.7%**	**0.0003**
Ulcerative colitis (RCU) (N=180)	15.0%	**85.0%**	
Irritable Bowel Syndrome (IBS) (N=34)	44.1%	55.9%	
Other conditions (N=11)	36.4%	63.6%	

Notably, individuals with IBS and Other Conditions reported a higher proportion of low impact on quality of life compared to those with Crohn's disease and ulcerative colitis, who predominantly reported a high impact on quality of life (See Figure 2).

Figure 2. Impact on QoL by intestinal condition.

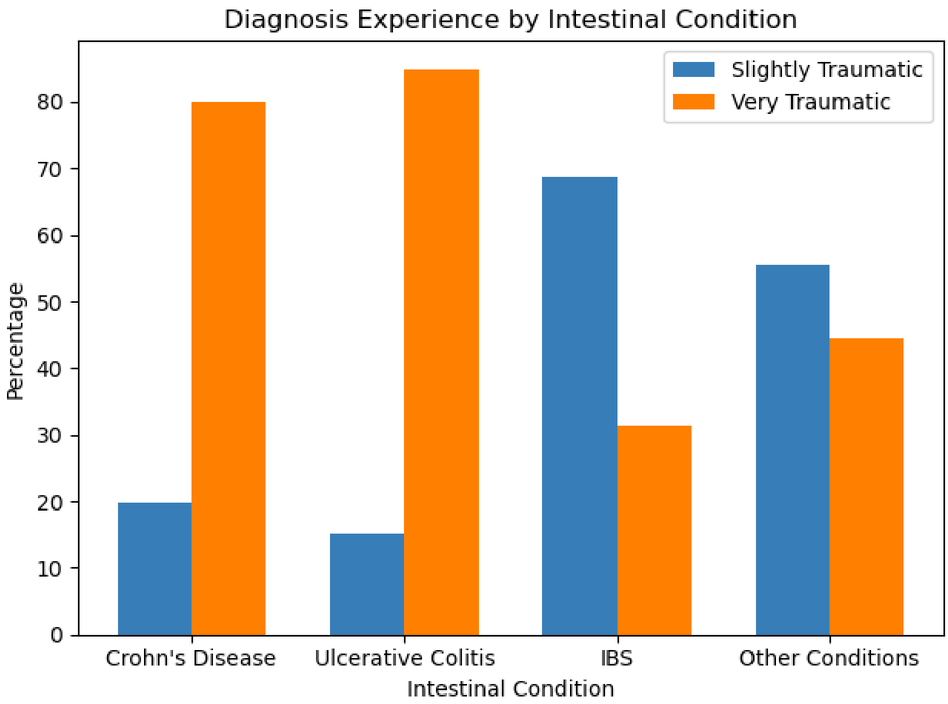


Regarding the experience of diagnosis as traumatic, the Chi-square test produced a value of $\chi^2 = 21.57$ with 12 degrees of freedom and a p-value = 0.043. This also indicates a statistically significant difference in how traumatic the diagnosis was perceived across the groups. Table 6 shows how IBS and other Conditions groups reported a less traumatic experience compared to Crohn's Disease and Ulcerative Colitis, where the majority found the diagnosis very traumatic (See Figure 3).

Table 6. The emotional impact of discovering a diagnosis of inflammatory bowel diseases (IBD).

Intestinal Condition	Slightly Traumatic (%)	Very Traumatic (%)	p-value
Crohn's Disease (N=111)	19.8%	**80.1%**	**0.043**
Ulcerative Colitis (RCU) (N=180)	15.1%	**84.9%**	
Irritable Bowel Syndrome (IBS) (N=34)	68.8%	31.3%	
Other conditions (N=11)	55.5%	44.4%	

Figure 3. Diagnosis experience by intestinal condition.



Qualitative analysis

Experiences and prevalent themes in Crohn's disease.

Table 7 provides a structured overview of the key aspects of living with Crohn's disease as shared by patients (28 segments).

Table 7. Experiences and prevalent themes in Crohn's disease.

Theme in Crohn's Disease	Contents
Diagnosistic difficulty	The lengthy and difficult process to diagnose Crohn's disease, with emphasis on the relief of finally having a name for their condition after years of suffering.
Impact on Daily Life	How the disease alters patients' nutrition, social activities, and general lifestyle.
Psychological and Emotional Stress	The mental health challenges, including depression and feelings of inadequacy or frustration due to the limitations imposed by the disease.
Adolescent Onset	The significant effect of the disease beginning in teenage years, influencing psychological and emotional development.
Chronic Nature	The realization and acceptance of living with a long-term, chronic illness.
Social Isolation	The loneliness and misunderstanding experienced by patients, and the fear from friends of causing discomfort, leading to social isolation.
Struggle with Normalcy	The desire to lead a 'normal' life despite the constraints of the disease and the need to manage expectations.
Physical Symptoms	The severity and disabling nature of the physical symptoms that come with Crohn's disease.
Healthcare Relationships	The importance of support from healthcare professionals, particularly gastroenterologists, and the potential need to change doctors for better care.
Resilience and Coping	Despite the challenges, a sense of resilience and the need to face the disease with a positive attitude.

The comments reflect personal experiences and the impact of the disease on patients' lives, including the psychological and emotional toll, the challenge of getting a diagnosis, the effect on daily life and social interactions, and the changes they've had to make in terms of diet and lifestyle.

Patients describe the onset of the disease during adolescence and its effect on their development, the severe and debilitating symptoms, the struggle with depression, and the challenges of dealing with a condition that is not always visible to others, which can lead to misunderstandings and feelings of isolation. The sentiment of relief upon getting a diagnosis after years of pain is also expressed, as it often provides a name to their suffering and a way to begin targeted treatment.

Experiences and prevalent themes in ulcerative colitis

The following table 8 summarizes the themes and contents from the comments on living with ulcerative colitis (52 segments):

Table 8. Experiences and prevalent themes in ulcerative colitis.

Theme in Ulcerative Colitis	Contents
Diagnostic Difficulties	Some comments highlight a long and complicated path to diagnosis, with feelings of relief mixed with fear once they received the name of their condition.
Impact on Daily Life	Many express how the disease has radically changed their life, affecting their ability to manage everyday life, social relationships, education, and work.
Side Effects and Treatments	Discussions around the difficulties in finding effective treatments and the side effects they may have, including the need for surgical interventions

Theme in Ulcerative Colitis	Contents
	when medications are no longer effective.
Emotional Experience	A strong emotional experience linked to the disease is perceived, with feelings of helplessness, fear, anxiety, and the sensation of being constantly followed by a shadow.
Subjectivity of Experience	Comments show how the experience of the disease is personal and different for each individual, with some feeling stronger in facing it and others experiencing a more devastating impact.
Reflections on Chronicity	Some reflect on the difficulty of accepting a chronic disease, especially when it manifests at a young age, and on how this affects their self-image and future plans.
Impact on Maternity	Some women discuss how the disease has affected pregnancy and maternity, adding an additional level of difficulty and concern.
Psychological Support	The need for adequate psychological support is indicated to help cope with the emotional and psychological challenges that accompany the disease.
Lack of Awareness	Some patients mention a lack of understanding and awareness by others regarding the severity of ulcerative colitis.

The qualitative analysis of patient narratives dealing with ulcerative colitis provides a richly textured understanding of the lived experience of this chronic condition. It reveals a constellation of psychosocial stressors and adaptive challenges that go beyond the physiological symptoms of the disease itself.

At the outset, the process of obtaining a diagnosis emerges as a critical psychological juncture. Patients frequently describe this period as fraught with uncertainty, compounded by a medical system that can be slow to provide answers. The eventual diagnosis, while providing some psychological relief by validating symptoms, simultaneously ushers in a new realm of uncertainty about the future. This duality underscores the complexity of the patient's experience at the point of entry into a life with a chronic illness.

As individuals navigate their daily lives with ulcerative colitis, the analysis unveils the pervasive impact of the disease on their existential reality. It influences their physical autonomy, often leading to a redefinition of self-identity and capabilities. The day-to-day unpredictability of symptoms necessitates a constant recalibration of personal and professional goals, highlighting the adaptive demands placed on patients.

Emotionally, the chronicity of ulcerative colitis engenders a spectrum of affective responses. The disease trajectory is often characterized by a fluctuating sense of helplessness and resilience. Affective states such as anxiety and depression are not uncommon, reflecting the ongoing psychological toll of managing a life-long condition. The narratives frequently refer to the shadow of the disease, a metaphor for the ever-present nature of the condition that shapes emotional well-being.

The subjective experience of the disease is also emphasized in the analysis, illustrating the idiosyncratic nature of the condition. While some individuals articulate a sense of empowerment and strength in their coping strategies, others convey a more debilitating impact, indicating the heterogeneity of the patient's experience.

Moreover, reflections on the chronic nature of ulcerative colitis often touch on the existential implications of living with a non-curable condition, especially when diagnosed at a young age. This aspect of the disease brings to light concerns about future life trajectories and the reconfiguration of long-term aspirations.

For female patients, the intersection of ulcerative colitis with maternity introduces a distinct set of concerns. The narratives provide insight into the compounded difficulties of managing the disease alongside the demands of pregnancy and motherhood, revealing a layered complexity of the female patient experience.

Lastly, the analysis points to a significant need for psychological support as part of comprehensive care. It highlights a gap in addressing the mental health needs of patients, which is crucial for improving overall QoL. The lack of societal awareness and understanding of ulcerative colitis also emerges as a key issue, with implications for patient advocacy and the need for public health education to mitigate stigma and foster a more informed and empathetic community response.

Experiences and prevalent themes in IBS

Table 9 presents a comprehensive overview of the common experiences and themes (5 segments) identified through research or patient reports related to IBS.

Table 9. Experiences and prevalent themes in IBS.

Theme in Irritable Bowel Syndrome (IBS)	Description
Struggle with a Disorder	Initial difficulty in managing a disorder, indicating a learning curve and adjustment period.
Learning and Coping	Adoption of measures to mitigate symptoms, showing resilience and proactiveness.
Impact of Stress	Stress exacerbates symptoms, highlighting the connection between emotional state and disorder severity.
Psychotherapy	Starting psychotherapy suggests a therapeutic approach to dealing with the disorder.
Hereditary Aspect	Condition is hereditary, affecting not just the individual but also their family.
Effect on Adolescence	Disorders have a limiting effect on adolescence, implying social, emotional, or physical restrictions.
Work-Related Discomfort	Work activities are related to the discomfort experienced, which may involve occupational challenges.
Family Impact	The individual’s mother also suffers from the condition, pointing to shared experiences within the family.

The themes and descriptions provided paint a detailed picture of the multifaceted experiences individuals with IBS may face throughout their lives. Each theme encapsulates a critical aspect of living with IBS, from the initial challenges of diagnosis and management to the broader implications on mental health, family genetics, adolescence, work, and family dynamics.

Experiences and prevalent themes in individuals awaiting diagnosis

These texts were produced by people without a clear diagnosis (2 segments) refer to the personal impact of a health condition characterized by stomach pain, its initial misinterpretation as a more serious condition, and the unpredictable nature of its episodes. It also reflects the difficulty of discovery and learning in managing the condition.

DISCUSSION

The study in question focuses on exploring the experiences and prevalent themes associated with four gastrointestinal conditions: Crohn's disease, UC, IBS and individuals awaiting diagnosis in the Italian panorama. This type of qualitative analysis provides an important perspective that goes beyond the collection of quantitative data, these analyses are valuable both in the clinical and research fields.

As underlined by Schoefs et al. [32] IBD patients discussed various unmet needs related to symptoms, side-effects, and psychological and social issues. Patients express a desire for more comprehensive information and communication from healthcare workers, underlining the need for a shared decision-making process and empathy in treatment [33].

IBD - but also IBS and Other conditions - significantly impacts the QoL of patients. The need to deal with debilitating gastrointestinal symptoms, frequent hospital admissions, surgeries, and long-term medical therapies can affect many aspects of daily life. Diet is one of the main aspects of daily life affected by IBD. Patients often need to follow specific diets to manage symptoms and prevent relapses [34]. This can involve dietary restrictions that significantly limit food choice and enjoyment. The social life of patients can be equally affected. The need to be near a bathroom at all times can limit participation in social events and outdoor activities.

As found in the study conducted by Jordan et al. [35] we identified themes related to anxiety including underperformance and worry and low mood. Furthermore, lack of understanding and stigma were prevalent.

Additionally, the stigma associated with gastrointestinal symptoms like flatulence or diarrhea can make social interactions embarrassing [36]. The work life of IBD patients can be compromised, especially in cases where symptoms are severe or unpredictable. Frequent absences from work due to exacerbations can lead to occupational and financial problems. Moreover, the stress caused by the illness can negatively affect job performance [37].

For these reasons, an IBD diagnosis can be perceived as an emotional trauma by patients. The confirmation of a chronic disease requiring long-term management can trigger a series of intense psychological reactions. The first reaction to the diagnosis can be shocked [38]. Patients may have difficulty believing they have a chronic illness and may experience a sense of disbelief and fear about the future. Anger is another common reaction to the diagnosis. Patients may feel angry about their situation, wondering "why me?". The anger can be directed towards themselves, fate, or even the medical system [39]. Sadness and depression can follow the diagnosis. Awareness of the chronic illness and the challenges it brings can lead to a sense of loss and a struggle against despair. Fear of the future is a very common reaction. Patients may worry about the consequences of the disease on their life, both physically and emotionally. The fear of future complications, surgeries, or dependence on medications can be overwhelming [40].

In the present study we found that Crohn's disease, recto colitis, and IBS share common aspects that shape the experience of individuals with these gastrointestinal conditions. To our knowledge this is the first study which compared gastrointestinal conditions, usually studied separately.

All three conditions are characterized by gastrointestinal symptoms, such as abdominal pain and changes in bowel habits, and they require long-term management due to their chronic nature. Patients often face challenging diagnostic journeys, leading to frustration and uncertainty. The impact on daily life is substantial, affecting work, social activities, and mental health, with many patients experiencing hyperarousal, anxiety and depression [41]. Building supportive relationships with healthcare providers is crucial in managing these conditions more effectively.

However, each condition also has unique features that set it apart. Crohn's disease often begins in adolescence, impacting the psychological development of young patients. It is known for its severe physical symptoms, including weight loss and fatigue, which can lead to social isolation. Resilience and a positive attitude are essential in coping with the challenges it presents [42].

A qualitative study conducted by Wu and colleagues [43] revealed themes of spiritual change, internalized supportiveness, cognitive reshaping, externalized behaviours, and future-oriented thinking, indicating the presence of posttraumatic growth in adolescents and young adults with IBD.

In contrast, proctitis is associated with side effects from treatments and may require surgery. Patients often experience strong emotions, and the impact varies widely among individuals. Some women may worry about the effect of proctitis on pregnancy, and there is a general lack of awareness about its severity [44]. For IBS, there is a learning curve to identify triggers and adopt coping measures, with stress exacerbating symptoms.

A qualitative study by Mirza et al. [45] highlighted the need for improvements in access to care, potential expansion of multidisciplinary care, and addressing psychosocial dimensions for patients and caregivers to deliver patient-centered care.

Understanding the specific patterns of diseases, as emerged through the qualitative analyses conducted in this study on Crohn's disease, UC, IBS, and subjects awaiting diagnosis, is crucial for timely identifying the aspects to intervene in patients suffering from these gastrointestinal diseases [46]. This knowledge can enable healthcare professionals to identify early signs of deterioration. For example, if it's recognized that patients with Crohn's disease often show an increase in anxiety before a worsening of symptoms, timely interventions can be made to manage stress and prevent a relapse [47].

Furthermore, understanding these specific patterns allows for the personalization of care based on individual patient needs. For instance, if it's known that patients with Ulcerative Colitis often experience guilt related to diet, specific specialist counselling support can be provided to alleviate this issue. Karadag et al. [48] found that patients experienced frustration and anxiety due to misdiagnosis or diagnostic delays. Post-diagnosis, many lacked detailed information about IBD from doctors.

Additionally, this knowledge can help efficiently direct clinical and psycho-educational resources. If it's understood that patients with IBS mainly face challenges related to communication with medical staff, efforts can be focused on communication programs and support.

Study limitations

This study, while insightful, is subject to certain limitations that must be acknowledged. One significant limitation is the prevalence of female participants, which may not accurately represent the gender distribution in the general population suffering from these gastrointestinal diseases. This gender imbalance could potentially skew the results and insights, especially if there are gender-specific experiences or responses to diseases that are not captured. Additionally, the geographical origin of the sample, being exclusively Italian, limits the generalizability of the findings to other cultural and ethnic backgrounds. This geographical homogeneity could overlook cultural differences in disease experience, healthcare access, and coping mechanisms.

Another notable limitation relates to the data collection method. The use of written narrative responses, rather than spoken interviews, may have constrained the depth of emotional expression. Non-verbal cues such as tone, pace, facial expressions, and body language—often critical in understanding a patient’s emotional and psychological state are inherently absent in written communication. This is especially relevant in conditions like IBD and IBS, where psychological well-being is closely intertwined with disease experience

CONCLUSION

The qualitative analyses conducted in the study provided a deep understanding of the personal experiences and prevalent themes among patients suffering from IBDs (Crohn's disease, UC), IBS and those awaiting diagnosis. These analyses highlighted emotional, psychological, and social aspects, including anxiety, depression, guilt, and social isolation, which significantly impacted the patients' daily lives, affective control and life satisfaction [49-53]. Moreover, the significant differences in experiences and themes among the various gastrointestinal conditions allowed for a more targeted personalization of therapies and clinical care, recognizing that challenges and needs can vary based on the specific condition. The analysis also revealed unmet needs, contributing to identifying areas where patient care could be improved, both through targeted psychological interventions and specific psychological, psychotherapeutic and somatic programs [54-59].

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