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Article

Pediatric Patients' Perspectives on Crohn's Disease: Insights into Disease Experience and Motivation for Self-Care

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Abstract: Introduction and objectives: Pediatric inflammatory Bowel Disease (IBD) patients often face challenges in coping and disease management, which can impact self-management. This study investigates these patients' conceptualization of the disease and motivations for self-management. **Methods:** Descriptive cross-sectional study using a self-administered, semi-structured online questionnaire applied to pediatric Crohn's Disease (CD) patients diagnosed>3 years, aiming to assess the impact of living with CD. **Results:** 10 patients included, 80% female, mean age 15.4 years, mean disease duration of 5.2 years. All patients were in remission with mean PCDAI of 3 (±4.8) and a mean IMPACT III score of 81.1). All patients reported good disease knowledge and adequate coping. Emotional responses at diagnosis included relief (60%) and negative emotions (40%). During relapses, anxiety and fear were prevalent, with 40% struggling with relapses. Therapeutic changes and monitoring were viewed as beneficial (100%) but with concern; 70% found monitoring tests a negative experience. Daily life impact was reported by 20%, with school accomplishments affected during relapses (40%). Extracurricular activities were limited during active disease (40%). Concerns about the future were noted by 40%, with 30% believing CD might limit their future. Most patients described appropriate self-efficacy: 60% self-managed, while 30% relied on parents. Transition to adult care was deemed necessary. **Conclusion:** This study illustrates the overall impact of disease on pediatric CD patients. It reports significant emotional and daily life challenges. The findings underscore the importance of psychosocial well-being, ongoing mental health assessment, non-invasive monitoring, and holistic care, emphasizing the patient perspective in managing pediatric CD.

Keywords: adolescent; Crohn's disease; health-related quality of life; inflammatory bowel disease; patient reported outcomes; pediatric; self-reported

1. Article Key Messages

What is already known on this subject: The patient perspective offers a valuable supplement to traditional clinical tools.

What does this study add: This study aims to understand pediatric IBD patients' experiences with the disease and what motivates them to manage their condition.

The findings indicate that the disease impacts patients' mental and emotional well-being, underscoring the necessity of addressing these aspects in disease management.

The research underscores the value of non-invasive monitoring tools in disease management, as they provide insights beyond traditional clinical measures, and the necessity of patient-centered care for pediatric patients with IBD, demonstrating that patient perspectives enhance treatment strategies and outcomes.

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2. Introduction

Pediatric IBD is a complex and challenging disease, frequently described as having a more aggressive phenotype compared to adult IBD [1], thus increasing the risk of poor outcomes. Although it can be diagnosed at a very young age [2,3], the diagnosis typically occurs during adolescence, forcing the patient to adapt to a novel reality of disease management, regular exposure to a healthcare team, and several treatments while dealing with the normal development changes of adolescence [4]. The impact of IBD on patients and their families can be profound, affecting not only their well-being but also their overall health and quality of life (HRQOL) [5,6]. Moreover, they may experience significant and chronic stress related to the unpredictable, painful, and potentially embarrassing symptoms associated with IBD [7] and the ongoing management of the disease [8], leading to maladaptive functioning, poor self-management, and poor health outcomes [8].

The family environment and support, the role of the caregiver, the social context, and the relationship with the healthcare team all play an important role in the effectiveness of pediatric patient self-management [8] and overall HRQOL.

Several pediatric studies have documented that pediatric IBD patients and their families experience impaired HRQOL in several physical and psychological domains, and also difficulties in autonomy related to disease activity, requiring specific coping strategies [9,10]. Previous research has also shown that adolescent patients' knowledge regarding their disease, treatments, and the ability to deal with healthcare systems is insufficient [4,11–14] and that pediatric patients tend to depend on their parents for disease management and medical decision-making. A recent study using questionnaires to describe the knowledge and self-efficacy skills of 80 IBD teenagers [15] further illustrated suboptimal knowledge regarding medications, smoking, and appointment management.

Knowledge of the disease and its management empowers pediatric patients and promotes better self-management and HRQOL, as it helps the patients to recognize, promote, and increase their ability to meet their own needs, solve their problems, and mobilize the necessary resources to take control of their lives [16]. This is particularly relevant to the clinical management of pediatric IBD patients, where parents play an important role as caregivers and primary reporters of the child's health status and symptoms and where the clinical team can easily overlook the pediatric patient's perspective. The focus of healthcare in IBD is evolving and becoming more comprehensive [17], including the assessment of physical and psychosocial functioning using patient-reported data and, in the pediatric context, respecting and promoting autonomy [18].

In this descriptive study, we aimed to explore and illustrate the disease perspective and the motivation for self-management behavior, considering the patients' disease conceptualization in a selected group of pediatric Crohn's Disease (CD) patients.

3. Materials and Methods

3.1. Study Design

This was a descriptive cross-sectional, single-site anonymous survey study, using a self-administered online questionnaire, conducted at a single reference center of pediatric gastroenterology. The participants were a subgroup of pediatric patients with CD who were simultaneously enrolled in another prospective study[19] and recruited during their scheduled appointments (convenience sample). The main cross-sectional study was developed to investigate the clinical usefulness and applicability of PROMIS by comparing and assessing the correlation between PROMIS and current assessment tools[19] and included 31 patients. Inclusion criteria included pediatric patients with CD who had been diagnosed for at least three years and were more than 12 years of age. Patients and/or their caregivers who did not wish to participate or sign the written consent were excluded, as were those with limitations in verbal or written comprehension of the Portuguese language, those younger than 12 years old, or those with a short disease course.

Before enrollment, informed consent was obtained from subjects older than 16 years and from the caregivers of subjects younger than 16 years (informed assent was also obtained from subjects

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younger than 16 years of age). Those who consented to participate received a link to the survey via email and completed it electronically at home. Confidentiality was ensured and there were no elements that could directly identify the patient.

The questionnaire could only be completed once and could not be accessed again. The data obtained were automatically converted into an anonymized database. The surveys were sent between April and August 2023, and answers were retrieved in a 2-week interval.

3.2. Questionnaire Data

The questionnaire, developed by the author, consisted of 45 open-ended and short answer questions (Table 1) aimed at assessing several items related to the experience of CD and its impact, including Knowledge about the disease; Description of the experience of the disease; Adaptation skills to the disease and to disease worsening; Secondary gains from the disease; School accomplishments, satisfaction, and motivation; Integration and social support; Perception of the future; Self-efficacy and transition of care. Patients were instructed to "tell their story of living with CD".

Table 1. Survey guide questions.

Knowledge of the disease
1. Do you know the name of your illness?
2. Do you know what your illness is?
3. Do you understand what the doctors and your family say about your illness?
4. Do you know how this illness is treated?
5. Do you know the names of the medicines you take?
6. Do you understand why you are being treated?
Description of the illness experience
1. How did you feel when you found out you had CD?
2. What has it been like for you to have CD?
3. Have you done anything to make it easier to cope with having CD?
Coping tools/skills and resilience in managing the disease (relapses/changes in treatment regimens, re-evaluation tests) and stressful life events (family, school, personal events)
1. How do you feel when the disease is not under control? How do you deal with it?
2. How do you feel when you have to change your treatment? How do you deal with it?
3. How do you feel when you have to undergo tests (Analysis, MRI, Endoscopy)?
4. How do you cope with the need of undergo testing?
5. How do you feel when you have to come in for appointments? How do you cope?
6. Do you think having CD makes your personal life, school and family life difficult?
Secondary gains from the disease
1. Do you think having CD has brought you any benefits at home, in your family?
2. And at school?
3. And with your friends?
School, school skills, satisfaction with school, motivation to go to school
1. Do you like school?
2. Do you find it difficult to keep up with the subjects?
3. Do you consider yourself a good student?
4. Do you have plans for your future at school?
5. Do you think having CD has affected your school performance in any way? Or your relationship with your classmates? And with teachers?
6. Have you changed your future plans because of your illness?
Social integration (peer acceptance)
1. Do you have friends at school?
2. And outside of school?
3. Do you feel different because you have CD?

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4. Do your friends know you have CD?
5. Do you think they treat you differently because of it?
Social support
1. Do you feel supported by your family? And your friends?
2. Do you think you need more support because you have CD?
Extracurricular and social activities
1. Do you feel restricted in any way by CD at school in your extracurricular and/or other leisure activities?
2. In which activities?
Perception of the future
1. Are you worried about your future?
2. Do you think having CD could limit your future?
Self-efficacy: Ability to perform a task successfully
1. Do you know what to do when you run out of medication?
2. Do you know how to contact your healthcare team?
3. Do you know what to do if you get worse from your illness?
4. Do you know the dates of your appointments and tests?
5. Who takes care of your illness, you or your parents?
6. Do you use an IBD app?
7. Do you research your illness online?
Transition of care
1. What do you think about the need to transition to adult care?
2. In your opinion, is there a better age to transition?
3. Do you think the transition should only happen when you are autonomous from your family (e.g., working)?

3.3. Other Data

Demographic data and disease-related data (Table 2) were collected from the patients' medical records and included gender, birth date, school level, and extracurricular activities. The levels of education were classified according to the International Standard Classification of Education [20] (ISCED 2011). ISCED 2011 has nine education levels, from level 0 to level 8. Disease-related data included age at diagnosis, years of disease, disease phenotype (Paris Classification) [21], Pediatric Crohn's disease Activity Index (PCDAI) [22] (disease activity score), need for steroid treatment, hospitalization and/or surgery, and current treatment at enrollment.

To measure HRQOL, we used Impact III [23], a 35-item self-report, IBD-specific measure of HRQOL, with lower scores indicating poorer HRQOL.

Patient-reported outcomes (PRO) were also assessed using short forms of pediatric PROMIS measures: global health, meaning and purpose, cognitive function, life satisfaction, peer relationships, depression, anxiety, pain interference, and fatigue. PROMIS measures are calibrated using a T-score metric with the mean of the original calibration population equal to 50 [20].

Table 2. Demographic and disease-related characteristics of the sample at recruitment.

Gender M/F (%)	2/8 (20/80)
Current age, years, mean (SD)	15.4 (± 2)
Level of education (ISCED)[a] n (%)	ISCED 2 (lower secondary education): 1 (10) ISCED (Upper secondary education) 3-5: 9 (90)
Extracurricular activities n (%)	4 (40)
Disease duration, years, mean (SD)	5.2 (± 3.6)
Age at diagnosis, years, mean (SD)	12.7 (± 3.4)
Time to diagnosis, months, mean (SD)	4.9 (± 3.6)
Paris, age at diagnose n (%)	A1a (<10 years) 5 (50) A1b (>10<17 years) 5 (50)

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PCDAI [b] mean (SD)	38.8 (± 16.9)
Paris, location n (%)	L2 (Colonic): 2 (20) L3 (Ileocolonic): 4 (40) L3L4a (Ileocolonic+ Upper discase proximal to Ligament of Treitz):4 (40)
Paris, phenotype n (%)	B1 (non-stricturing non-penetrating): 9 (90) B3 (Penetrating): 1 (10) Perianal disease 2 (20)
Paris growth n (%)	G0 (No evidence of growth delay): 6 (60) G1 (Growth delay): 4 (40)
Need of hospitalization n (%)	
At diagnosis	6 (60)
Readmission during follow-up (N=6)	3 (50)
In the prior 6 months [c]	0
Need of surgery n (%)	
At **diagnose**	1 (10)
In the prior 6 months [c]	0
Current treatment n (%)	Immunomodulator 3 (30) Anti-TNF alfa [d] treatment 5 (50) Ustekinumab [e] 2 (20)
Treatment modifications n patients (%)	
During follow up	4 (40)
In the prior 6 months [c]	0
Need of corticosteroids n (%)	0
Poor compliance to treatment - n (%)	0
PCDAI [b] mean (SD)	3.0 (4.8)
Fecal Calprotectin µg/g, mean (SD)	424.8 (563.4)
IMPACT III [f] mean (SD)	81.1 (13.1)

a: ISCED - International Standard Classification of Education: ISCED 0-2: Lower secondary education, ISCED 3-5: Upper secondary education, ISCED > 6: Higher educations; b: PCDAI - Pediatric Crohn's disease Activity index: scoring < 10 was considered in remission; c: In the 6 months before recruitment; d: TNF - Tumoral Necrosis Factor: e: After failing 2 previous biological treatments; f: IMPACT III: 35-item self-administered questionnaire of health-related quality of ~~Life~~ in pediatric IBD, score ranges from 35 (poor) to 175 (best).

3.4. Statistical Analysis

Descriptive statistics, including means and standard deviations, as well as absolute and relative frequencies, were used for patient demographic and disease-related characteristics and analysis of patients' perceptions documented in the survey answers.

The transcribed answers were analyzed to identify response patterns/themes that would allow different perspectives to be established. Although no formal qualitative analyses were performed in the current study, the following steps were conducted:

- Reading and re-reading the transcripts and identifying meaningful segments of text;
- Identifying themes/patterns of response within each main group;
- Reviewing themes//patterns to ensure they were clear;
- Selecting clear and vivid examples that relate to the research question.

4. Results

15 patients, fulfilling the inclusion criteria, were invited and agreed to participate, and 10 responses were obtained (response rate of 66,6%). Table 2 summarizes the demographic and clinical characteristics of the pediatric CD patients who participated in the survey.

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The sample consisted of 80% females with an average age of 15.4 years (± 2), with upper secondary education (90%). The mean age at diagnosis was 12.7 years (± 3.4), and the mean disease duration was 5.2 years (± 3.6). Most patients (40%) had ileocolonic involvement, a non-stricturing, non-penetrating disease phenotype (90%), without perianal disease (80%). Evidence of growth delay was observed in 40% of patients**;** mean PCDAI at presentation was 38.8 (± 16.9); 10% of patients were on biological treatment at diagnosis.

In this sample, patients experienced symptoms for a mean period of 4.9 months (± 3.6) until CD diagnosis. At diagnosis, 60% were hospitalized, and one patient (10%) needed surgery due to CD fistulizing disease. Biological treatment is the current treatment in 70% of the patients, and all were in remission, with a mean PCDAI score of 3 (± 4.8). In the prior 6 months prior to enrollment, the disease was stable in all patients. The patients expressed a good HRQOL, reflected by a mean IMPACT III score of 81.1 (± 13.1), and an overall good global, mental, and physical health reported by PROMIS scores (Table 3).

Table 3. Patient reported Outcomes (PROMIS measures) at recruitment.

PROMIS Measure	Mean (SD)
Global Health	47.1 (13.4)
Depressive symptoms	42.5 (12.1)
Anxiety	39.7 (10.4)
Pain interference	43.3 (7.5)
Fatigue	46.8 (14.7)
Life Satisfaction	44.2 (7.4)
Meaning and Purpose	47.0 (9.6)
Cognitive function	46.7 (11.6)
Peer Relationships	46.8 (13.9)

Knowledge of the disease; Description of the experience of the illness; Coping tools/skills and resilience in managing the disease (Supplemental material, Tables S1–S3)

All patients reported being aware of the disease and understanding the information provided by the healthcare team. Ninety percent knew and understood their therapy rationale.

The diagnosis of IBD was met with feelings of relief by 6/10 (60%) of respondents, while 4/10 (40%) expressed negative emotions (fear, anxiety, revolt, anguish). However, only 1/10 (10%) of patients sought specialized help to deal with the diagnosis. Anxiety, fear, and loss of energy were reported by 5/10 (50%) of respondents when the disease was not under control, and 4/10 (40%) found it difficult to cope with relapses.

> ***Patient 7:*** *"I was only 14 and had no idea what it meant to have it, so I felt fear and sadness when realizing that I was going to have 'something bad' accompanying me for the rest of my life. After talking to the doctor, I realized that there was no need to be so afraid because I could control the disease (…)"*

Concerning therapeutic changes, all patients view them as necessary and positive, although 3/10 (30%) express concern about the change.

> ***Patient 7:*** *"I'm afraid that I'm regressing, and as a rule, the treatment is always 'worse' than the previous one. But I usually manage as well as I can…"*
>
> ***Patient 8*** *"…I usually don't mind too much because I'm already in the mindset, and I know it's best for me…"*

Tests related to monitoring the disease are viewed as a negative experience by 7/10 (70%) of patients and are related to the need for a venous puncture, length of time (MRI), and the need for preparation (endoscopic procedures). These tests elicit fear, anxiety, and anguish in the patients, particularly with the more invasive tests.

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Patient 5*"….When I have to perform exams, I get frustrated. I hate being in the hospital for a long time, and the tests end up forcing me to stay there for a long time. I don't like the environment I'm subjected to, I feel like I'm just another sick person. I feel weak. The atmosphere leaves me feeling drained and very discouraged…"*

Four patients (40%) expressed a dislike for attending IBD monitoring appointments, citing boredom, discomfort, and anxiety as reasons for their aversion.

Patient 1*"…. I feel fine, but I'm always a little afraid of what I might hear or if they're going to tell me that the tests aren't good…"*

Patient 7: *"Sometimes, it's annoying because it gets in the way of day-to-day commitments, but I like to be accompanied so that I have an idea of how I'm doing."*

Secondary gains from the disease (Supplemental material, Table S4)

It was observed that 2/10 (20%) of participants reported that having CD affects their professional, family, and school lives. However, when queried, 6/10 (60%) of respondents indicated that it had not brought about secondary gains in the home (60%), at school (80%), or with friends (100%).

Patient 4: *"I think it's more the other way around. It's personal life, school, and family life that end up making Crohn's disease more difficult. Many stressful events throughout life end up causing many bouts of diarrhea…"*

School, school skills, satisfaction with school, motivation to go to school (Supplemental material, Table S5)

Regarding school and academic performance, 9/10 (90%) of participants expressed a positive attitude towards school. Of these, 7/10 (70%) considered themselves to be good students with good academic performance. Furthermore, all participants reported having future academic plans that had not changed despite the diagnosis of CD. Forty percent of the respondents indicated that relapses of the disease have an impact on their academic performance.

Patient 8 *"…As for school performance... when my illness isn't under control, it's difficult to stay focused and study for tests, which ends up making my school performance very difficult…"*

Despite having friends both inside (90%) and outside (100%) of school and the fact that their friends are aware of their diagnosis and say that they are not treated differently, 3/10 (30%) of the respondents reported feeling different from their peers. 1/10 (10%) of respondents indicated that they have chosen to conceal their diagnosis from others, mentioning concerns about potential discrimination.

Patient 5: *"Nothing has changed because despite having the disease, I can do everything I did before. I've kept up my school performance, and it's even improved. I've maintained good relationships and even made friends, and relations with teachers have remained the same…"*

Social integration and social support, Extracurricular and social activities, Future perspectives (Supplemental material, Tables S6–S9)

All respondents indicated that they have family and extra-family support. Furthermore, 9/10 (90%) of respondents indicated that they believe that support is sufficient.

All individuals have engaged in extracurricular activities and/or regularly engaged in sports, although 40% have indicated that their CD has limited their participation in physical and leisure activities during periods when the disease is active. The primary limiting factor cited by these individuals is a lack of energy 3/10 (30%) and abdominal pain 1/10 (10%).

Patient 6 *"…When the disease is not under control, I find it extremely difficult to get out of bed and do leisure activities. I like hanging out with friends, traveling with family, going to the beach... these kinds of things become complicated when the disease is not under control…"*

Four out of ten individuals express concerns about the future. Of these, three out of ten believe that their CD may limit their future.

Self-efficacy: Ability to perform a task successfully (Supplemental material, Table S10)

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In evaluating their self-efficacy in managing the disease, 6/10 (60%) of respondents indicated that they were aware of the appropriate course of action to take in the event of a therapeutic supply shortage. However, 4/10 (40%) of respondents expressed uncertainty regarding the means of contacting the medical team. Three participants (30%) were unable to provide the dates of scheduled appointments and examinations. However, 6/10 participants (60%) considered themselves responsible for managing the disease, while 3/10 (30%) delegated responsibility to their parents. None of the respondents use apps to assist in managing their disease. However, 60% admitted to conducting online research on CD to enhance their understanding of the disease.

Transition of care(Supplemental material, Table S11)

Regarding the transition from pediatric to adult care, five participants (50%) expressed no opinion on the subject, while all agreed on the necessity of the transition and accepted it.

> ***Patient 1*** *"…I haven't given it much thought yet, but I consider it a step of greater responsibility…"*

Regarding the age of transition, 9/10 (90%) of respondents could not define an ideal age, while 3/10 (30%) considered it desirable to be "later," "when independent," or dependent on individual characteristics (personalized transition).

> ***Patient 3*** *"…I have no idea. But I think it depends on each person".*
>
> ***Patient 4*** *"…The later the better…"*

Fifty percent (5/10) of respondents believed that the transition to adulthood should only take place when they achieve economic independence from their family.

5. Discussion

In this study, we conducted a comprehensive exploration of the patients' experiences with their illnesses across various domains of their lives. Our focus was on the patients' knowledge about their illnesses, their personal experiences related to the diagnosis, and their abilities to adapt to their illnesses, disease management, and potential worsening. Additionally, we considered potential secondary gains associated with the illnesses, as well as their impact on the patients' academic, familial, and social lives. Furthermore, we aimed to investigate self-efficacy, perceptions of the future, and comprehension of the transition of care. Our research allows us to gain a deeper understanding of the meaning of living with CD from a pediatric patient's perspective.

Our results demonstrate that, despite the long disease course, good disease knowledge, good control of CD, and good global HRQOL reported by the study group, the majority of patients report the experience and the process of CD diagnosis as being hard, difficult, and emotionally demanding. Moreover, they still experience difficulties in coping when the disease is not under control, with some impact on school performance, leisure activities, and sports. Only a minority of respondents expressed emotional distress related to a disease relapse, which highlights that we are possibly identifying just the iceberg tip and the importance of assessing psychological risk in these patients. However, the patients of this study are optimistic when referring to the present impact of living with CD.

These results support the current recommendations regarding the importance of the psychosocial well-being of pediatric IBD patients, with improvement of QOL and absence of disability being defined as part of treatment goals of IBD [17]. It is recommended that the psychosocial status, mental health, and quality of life of children with IBD and their families should be assessed [24], as these patients are at risk for mental illness associated with their disease.

The negative impact on the psychosocial functioning and HRQOL in pediatric IBD is widely reported in the existing literature [9,10,21]. Difficulties in autonomy domains related to disease activity have also been documented, requiring specific coping strategies [9,10].

Interestingly, the respondents have manifested a strong engagement in disease management, as they consider themselves capable of managing most of the tasks related to their illness, regardless of having parents as caregivers. Another interesting finding emerging from the survey responses is the

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impact on well-being caused by the clinical assessments of disease and treatment changes. Although most patients understand and recognize the importance of disease monitoring and treatment modifications in achieving treatment goals, they report discomfort and fear induced by several exams, as well as the inconvenience of medical appointments, and the need to go to the hospital.

Disease monitoring is mandatory in IBD. The recent Treat- to-Target strategy [17] relies on close disease monitoring and frequent reassessment of disease activity to achieve therapeutic goals. Achievement of mucosal healing is associated with long-term remission and consequently better health-related outcomes, with a positive impact in the lives of the patients [25]. However, there is no consensus on when to re-evaluate disease activity after inducing remission. Simultaneously, non-invasive monitoring is becoming increasingly significant to assess disease activity [25] including small-bowel imaging and fecal calprotectin. Telemonitoring IBD is also advancing as a disease monitoring tool [26], including using of PROMs, home-based tests and wearables devices, with benefits to patients, including, improvement in QOL, a reduction in the number of days lost from school and work, better disease knowledge, with a good cost-effectiveness profile [26]This is also highlighted by this study, where the detrimental impact of invasive testing became evident.

Our study also highlights the importance of including the patients' perspective on their health condition, treatments, and disease management, which is the definition of Patient Reported Outcomes (PRO's). The inclusion of PRO's is recommended as a good model of patient-centered care [17,24].

The results of this study also suggest that patients are aware of the importance of the transition of care but still have limitations in conceptualizing it. This is understandable, as the transition from pediatric to adult care represents a vulnerable period for these patients, which frequently are still adapting to all the disease particularities and integrating them in their daily lives. Although the correct age for transition remains to be defined, growing evidence suggests that the age should be individualized and determined by the existence of all the skills and knowledge necessary for proper disease management, thus ensuring better outcomes [4,11,12]. The medical team should adequately prepare the pediatric patient for the transition of care as part of a comprehensive model of care.

One limitation of our study is the questionnaire-interview design. Unlike a traditional face-to-face interview, this approach involved online open-ended questions and a personalized approach. The necessity to address the time constraints associated with conducting interviews led to a decision to implement this approach.

Another potential study limitation is the disease activity and the deliberated absence of recent diagnose patients. We, however, consider that despite having a well-controlled disease, this group of patients, with a relative long disease course, had different course of illness and experienced periods of exacerbation, allowing for the acquisition of a realistic, critical, and objective perspective of their illness and the strategies they had developed over time to cope with it.

Obtaining this perspective may be challenging in patients with a recent diagnosis or in those experiencing a period of particularly active disease. The present study was mainly assumed as qualitative narrative of pediatric CD patients, illustrating their experience with a chronic disease. Finally, the female gender predominance, limits the generalizability of the findings.

Despite these limitations, this qualitative study aimed to contribute to the comprehensive understanding of the effect of a chronic illness on a patient's life, particularly in pediatric patients, where data assessing of patients' understanding of IBD are emerging [13,15].

Future research should aim to include more representative samples of pediatric IBD population, encompassing different CD and ulcerative colitis phenotypes and integrate patient insights and perspectives in future PROMIS tools.

6. Conclusions

In conclusion, our study further provides a comprehensive and lived illustration of the multifaceted experiences of pediatric patients living with CD. Despite a long disease course and good overall knowledge of the disease, patients report significant emotional challenges and difficulties at

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diagnosis and during periods of disease flare, affecting various aspects of their lives, including academic performance, leisure activities and sports. These findings are in accordance with recently published evidence. While most patients demonstrate strong disease management and adaptative skills, as well as resilience and optimism about their current condition, the psychological distress associated with disease relapse underscores the need for ongoing mental health assessment. Our findings highlight the critical importance of psychosocial well-being as a treatment goal and the incorporation of PROs for patient-centered care. In addition, the study underscores the need for non-invasive disease monitoring methods (including telemonitoring tools), especially in pediatric populations. Overall, our study provides valuable and lived insights into the pediatric CD experience, highlighting the need for holistic care approaches that address both medical and psychosocial patient-centered features.

Supplementary Materials: The following supporting information can be downloaded at: Preprints.org.

Author Contributions: All authors read and approved the final manuscript. Conceptualization, data curation, investigation, methodology (SA), formal analysis (SA, LR) supervision: (AIL), validation: (AIL). The first draft of the manuscript was written by (SA) and all authors commented on previous versions of the manuscript.

Author Contributions: All authors read and approved the final manuscript. Conceptualization, data curation, investigation, methodology (SA), formal analysis (SA, LR) supervision: (JV, AIL), validation: (JV, AIL). The first draft of the manuscript was written by (SA) and all authors commented on previous versions of the manuscript.

Ethics Approval and Consent to Participate: The study was conducted in accordance with the ethical principles set forth in the Declaration of Helsinki of the World Medical Association and in accordance with the additional requirements set forth in the national legislation. Prior to the commencement of the study, ethical approval was obtained from the Ethical Committee of Santa Maria University Hospital - CHLN, Academic Medical Centre of Lisbon, Portugal.

Patient Consent Statement: Informed consent was obtained from subjects older than 16 years and from the caregivers of subjects younger than 16 years (informed assent was obtained from subjects younger than 16 years of age). Those who consented to participate received a link to the survey via email and completed it electronically at home.

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List of Abbreviations

Crohn's Disease (CD), Health-Related Quality of Life (HRQOL), Inflammatory Bowel Disease (IBD), Patient Reported Outcomes (PRO's), Pediatric Crohn's Disease Activity Index (PCDAI), Quality of Life (QOL).

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