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J Pediatr Gastroenterol Nutr. Author manuscript; available in PMC 2018 October 01.

Published in final edited form as:

J Pediatr Gastroenterol Nutr. 2017 October ; 65(4): 420–424. doi:10.1097/MPG.0000000000001549.

Psychological distress and quality of life in pediatric Crohn's disease: Impact of pain and disease state

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Abstract

Objectives—For patients with Crohn's disease (CD), symptom reporting may not coincide with disease state; patients in remission may continue to report symptoms and pain, while other patients may be symptom-free despite a flare. This phenomenon has been documented in adults but only recently assessed in pediatric patients. This study assessed the role of pain reporting and disease state in pediatric patients with CD in understanding psychological distress and quality of life.

Methods—Participants included 116 children and adolescents ages 8-18 with CD who completed self-report questionnaires assessing pain, disease symptoms, depression, anxiety, functional disability, and quality of life. Physicians completed the Pediatric Crohn's Disease Activity Index to assess disease activity (scores ≤10 =remission, scores >10=flare).

Results—Approximately two-thirds of participants reported pain concordant with disease state. For patients in remission, those with pain experienced significantly increased disability and

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Conflicts of Interest: The authors have no conflict of interest related to the current work.

Authorship Contributions: Robyn Lewis Claar: Dr. Claar provided statistical analysis and data interpretation, drafted the initial manuscript, reviewed and revised the manuscript, and approved the final manuscript as submitted.
Miranda A. L. van Tilburg: Dr. van Tilburg assisted with study design and concept, provided statistical analysis and interpretation of data, critically reviewed and revised the manuscript and approved the final manuscript as submitted.
Bisher Abdullah: Dr. Abdullah assisted with study design and concept, acquisition of data, review and revision of the manuscript and approved the final manuscript as submitted.
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Douglas Drossman: Dr. Drossman assisted with critical review and revision of the manuscript and approved the final manuscript as submitted.
Rona Levy: Dr. Levy assisted with study design and concept, funding, acquisition of data, study supervision, critical review and revision of the manuscript and approved the final manuscript as submitted.
All authors approved the final version of this manuscript.

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decreased quality of life compared to patients in remission without pain. For patients in a flare, those without pain experienced significantly decreased disability and depressive symptoms, as well as improved quality of life compared to patients in a flare with pain.

Conclusions—For pediatric patients with CD, report of pain, while in remission or a flare, is associated with increased disability and reduced quality of life. While levels of depression did not differ by disease state, depressive symptoms did differ by pain report (presence or absence) for those in a flare. Pain reporting in CD appears to be associated with both physical and psychological state and should be assessed regardless of disease activity.

Keywords

Pediatric Crohn's Disease; Pain; Psychological Factors; Quality of Life

Introduction

For patients with Crohn's disease (CD), inflammation causes symptoms such as pain, gas, and diarrhea. These symptoms can significantly affect patients' quality of life, and previous research in adults has demonstrated an association between increased inflammation and decreased quality of life (1). However, some patients with inflammatory bowel disease (IBD) report higher levels of symptoms than others, and symptom reporting may not mirror disease state or physician ratings of inflammation (2,3,4). For example, several studies have documented functional bowel symptoms in adult patients with quiescent IBD (5,6,7,8), a phenomenon called IBD-IBS (9). In addition, discordance between patient and physician perceptions of physical health is associated with negative outcomes in adult IBD patients (10,11), particularly for patients experiencing psychological distress (12,13,14). Psychological distress is a stronger predictor than bowel symptoms of decreased quality of life for adult patients with IBD (15,16).

Less is known about pediatric patients. Two studies classified pediatric IBD patients by disease activity and pain (17,18). IBD-IBS overlap varied considerably between these studies (5.8% vs. 29.5%). Pain was associated with increased depressive symptoms (17) and decreased quality of life (18) even when taking disease activity into account. In addition, a recent study found that in pediatric patients with IBD, over half of participants reported abdominal pain, and the majority of those patients reporting pain had no evidence of clinical disease activity (18).Thus, there is some evidence that abdominal pain is an important predictor of outcomes in pediatric IBD.

The present study sought to replicate and build on these previous findings by assessing the frequency of concordance between patient-reported pain and disease state (remission versus flare) in pediatric patients with CD. Previous studies have mainly focused on the group of patients who report pain while in remission (IBS-IBD patients) but discordance also can occur when patients with active disease are asymptomatic. This is a group that has not been studied in detail. In addition, we sought to better understand whether pain-disease state discordance was related to patients' psychological distress and quality of life, as there is limited assessment of these constructs in a pediatric population. We focused on the assessment of abdominal pain, as it is the most common symptom associated with CD (19),

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and pain may remain despite absence of inflammation and normalization of mucosal lesions (4, 20) and in patients thought to be in remission (17). In addition, pain often is associated with increased psychological distress and decreased quality of life across a number of medical conditions (21). We hypothesized, consistent with the adult literature, that pain-disease state discordance would be associated with increased psychological distress, disability, and decreased quality of life. In addition, we hypothesized that patients reporting pain in remission would experience decreased quality of life and increased psychological distress, while absence of pain during a flare would be associated with increased quality of life and decreased psychological distress.

Methods

Please see the supplemental digital content for a description of the Methods for this study.

Results

Sample characteristics

The data for the current study are part of the baseline assessment for a randomized controlled trial of cognitive behavioral therapy for children and adolescents with CD and ulcerative colitis (UC). Of those 126 participants with CD in this study, 116 patients had both physician ratings of disease activity (from the PCDAI) and self-reports of pain (from the FPS) that were used to categorize the patient groups in this study. Participants included 116 children and adolescents ages 8-18 (57.5% boys, 93.0% Caucasian, mean age 13.8). One participant did not complete the anxiety and depression questionnaires and was excluded from analyses with those variables. No other missing data were encountered. Time since diagnosis for participants in this study ranged from 3 to 182 months, with a mean time since diagnosis of approximately two years (M=24.69 months, SD = 25.35). Twenty-four patients (20.7%) were prescribed a corticosteroid medication for treatment of their CD; 39 patients (33.6%) were prescribed an immunosuppressant; 36 patients (31.0%) were prescribed anti-TNF treatment; and 6 patients (5.2%) were prescribed a pain medication. In addition, 24 patients (20.8%) had surgical treatment of their CD; 16 patients had one surgery while 8 patients had two or more surgeries.

Association of medical and surgical treatment with patient report of pain and quality of life

A series of unpaired t-tests was used to examine whether patients' use of medications and surgical treatments was associated with their report of pain and quality of life. There were no differences in pain for patients prescribed immunosuppressants (M=.77) versus those who were not (M=.94) or for patients with past surgical treatment of CD (M=1.00) versus those without past surgical treatment (M=.83). However, patients prescribed anti-TNF treatment reported lower levels of pain (M=.39 vs. 1.12, $p<.001$) than patients who were not prescribed this treatment. There were no differences in quality of life associated with patients' use of immunosuppressants (M=80.04 vs. M=79.85, p=n.s.), anti-TNF treatment (M=82.24 vs. 78.81, p=n.s.) or past surgical treatment (M=74.87 vs. 81.04, p=n.s.).

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Impact of disease state on psychological functioning and quality of life

Physician ratings of disease activity on the PCDAI were used to categorize patients' disease state as in remission (n = 80) or in a flare (n = 36). Unpaired t-tests were then used to compare the two patient groups on the study variables of interest. As expected, we found that compared to patients in remission, patients in a flare reported higher levels of disability (M=9.86 vs. 4.60, p<.05), bowel symptoms (M= .66 vs. .38, p < .01), anxiety (M=47.63 vs. 39.08 p<.01), and reduced quality of life (M=71.99 vs. 82.98, p<.001). There was no difference in depressive symptoms by disease state.

Pain and disease concordance

We next examined the frequency of each IBD symptom on the IBDS for the total sample. As expected, pain was the most commonly endorsed symptom (53.4%), followed by gas (48.3%), diarrhea (40.5%), and frequent trips to the bathroom (39.7%). We then categorized the sample into four groups by pain (present or absent) and disease state (remission or flare); see Table 1. Approximately two-thirds (67.2%) of participants reported pain concordant with their disease state [e.g., absence of pain in remission (54.3%) or pain with a flare (12.9%)]. Report of pain discordant with disease state occurred less frequently. Girls in a flare (n = 15) reported higher levels of pain (M=2.00, SD=1.69) compared to boys (n =21, M = .57, SD=1.12 p < .01); no other differences were found by gender or age.

We also planned to assess whether disease concordance would be impacted by disease location and severity as categorized by physicians' Paris classification ratings. However, because there were so few CD patients in each classification group, subsequent analyses were limited. To assess concordance ratings in patients with more severe disease activity, we combined those patients in the disteal ileum group (n=31) and the ileocolonic group (n=45). Similar to the results with the total sample as described above, we found that approximately half of participants (55.3%) with ileal involvement reported pain concordant with their disease state [e.g., absence of pain in remission (48.2%) or pain with a flare (7.1%)]. Paris classification data are presented in Table 2.

Association of pain and disease state discordance with psychological distress and quality of life

A series of one-way ANOVAs was conducted to compare the four groups (remission without pain, remission with pain, flare without pain, flare with pain) on the variables of interest; results are shown in Table 3. Post-hoc tests with Bonferroni corrections revealed that reporting of pain while in remission was associated with increased disability (M=10.65 pain vs. M=2.97 no pain; p<.001) and decreased quality of life (M=72.85 vs. 85.72; p<.010). When patients reported pain, even though their disease was in remission, they experienced higher levels of disability, and lower levels of quality of life. Absence of pain during a flare was associated with decreased disability (M=6.76 no-pain vs. 14.20 pain; p<.01) and depressive symptoms (M=6.02 vs 13.95; p<.01), as well as increased quality of life (M=79.41 vs 61.60; p<.001). When patients were in flare but did not experience pain, they experienced lower levels of disability and depressive symptoms. Presence or absence of pain during a flare was not associated with levels of anxiety; the only significant post-hoc

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comparison for anxiety indicated that patients in a flare with pain experienced significantly higher levels of anxiety than patients in remission without pain.

Disease status and patient report of IBD symptoms

We also examined whether the four patient groups differed in their report of other IBD symptoms; see Table 3. After re-computing the total IBD symptom scores without abdominal pain, a one-way ANOVA revealed significant differences in other IBD symptoms across the four patient groups, $F(3, 112) = 13.82$, $p < .001$. Post-hoc tests with Bonferroni corrections indicated that patients in a flare with pain reported significantly higher levels of other IBD symptoms ($M = .87$, $SD = .44$) compared to patients in a flare without pain ($M = .33$, $SD = .25$, $p < .001$) and patients in remission without pain ($M = .24$, $SD = .34$, $p < .001$).

Discussion

Most pediatric patients with CD report pain concordant with their objective disease state. This finding is encouraging, as previous research among adult patients demonstrates that concordance between patient-symptom reports and physician ratings of disease is associated with more adaptive outcomes, while discordance is associated with increased distress and decreased quality of life (10, 11). We found similar findings in children and adolescents. When pain reporting is discordant with disease state, higher levels of pain are associated with increased disability and decreased quality of life.

Approximately 15% of our sample experienced pain while in remission. Pain reporting in remission in pediatric patients with CD has been documented in other studies as well (17,18, 33). One explanation for this phenomenon may be that the presence of pain while in remission is influenced by patients' psychological functioning rather than their disease state. Long and Drossman (4) noted that psychological distress may impair sensory signaling processing, which in turn may be associated with increased perception of pain. Interestingly, we found that depressive symptoms differed by pain report and not disease activity. Specifically, we found that those patients in a flare with pain experienced significantly higher levels of depressive symptoms than those patients in a flare who were pain-free. These findings highlight the importance of measuring pain in addition to understanding patients' disease state, as it appears that the presence of pain with active disease, rather than active disease alone, may place these patients at higher risk for emotional distress or that increased emotional distress may in turn color patients' report of pain. In fact, Zimmerman et al., (17) recently found that the experience of abdominal pain, rather than disease activity, was associated with higher levels of depression for pediatric patients with CD. Similarly, Srinath and colleagues (35) found that depression, rather than biological disease markers, was associated with reports of abdominal pain for pediatric patients with CD. Alternatively, the experience of pain in remission may be due to visceral hypersensitivity or autonomic dysfunction that is secondary to chronic inflammation (36).

Recently, Wojtowicz et al. (37) found that pediatric patients with active *and* quiescent IBD reported experiencing abdominal pain and that pain severity and catastrophizing about pain (thinking the worst) were associated with increased functional disability for these patients. Similarly, Greenley and colleagues (18) found that the presence of abdominal pain in

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pediatric patients with both active IBD and IBD in remission was associated with decreased health-related quality of life. Our findings replicate and extend this research, as we sought to understand how both pain and disease concordance influence quality of life. We found that those patients in a flare with pain had the lowest quality of life followed by those in remission with pain while patients without pain had the best quality of life. Our results reinforce the recommendations made by Garrett and Drossman (2) to assess both disease activity *and* psychosocial status to accurately and comprehensively understand well-being for patients with IBD.

For patients experiencing a flare, pain may be indicative of more significant disease, and physician and patient ratings of IBD symptoms are significantly correlated. Indeed, we found that patients in a flare with pain experienced significantly higher levels of all other IBD symptoms compared to patients in a flare without pain. Not surprisingly, we found that girls experiencing a flare reported higher levels of pain; past research with a variety of chronic pain conditions, including IBD (18) has demonstrated that girls may be at greater risk for pain than boys (38).

In addition, we found that for those patients experiencing a flare without pain, concordance between patient-reported IBD symptoms and IBD disease activity is low, indicating that perhaps these patients underreport or minimize their symptoms or that physicians may expect these patients to experience more symptoms based on objective disease activity. It is important to note that unlike ulcerative colitis in which level of inflammation can be expected to more readily correlate with symptoms, CD by nature is associated with greater clinical variation, making it more difficult for physicians to assess (2), which in turn may be associated with lower levels of concordance between patient and physician report of symptoms. In addition, physician ratings on the PCDAI may be less influenced by pain; the majority of items on the PCDAI do not assess pain-related disease activity, as inflammation may be painless in the absence of a blockage or ulcerations. However, Zimmerman et al. (17) noted that because the PCDAI assesses functional symptoms, disease severity scores can be elevated for patients in clinical remission who continue to have functional symptoms, thereby introducing additional variability in concordance ratings. Alternatively, perhaps these patients experience decreased pain in the context of more adaptive psychological and physical functioning, given the subjective nature of pain perception. Taken together, our results underscore that pain reporting in CD appears to be associated with both physical and psychological state.

Our findings must be interpreted in the context of study limitations. First, this study is cross-sectional and therefore it is not possible to determine causal relationships. Second, although pain is the most common symptom reported in CD, and most of the participants' reports of pain were concordant with their disease state, it is possible patients may experience bowel symptoms without pain and therefore patient-disease discordance may not be fully captured by using pain ratings alone. Future studies that include daily diary ratings of pain also may be helpful and would eliminate any potential recall bias. Future research that assesses concordance with identical assessment items for both patients and physicians may be useful in understanding how patient-physician perceptions influence psychological functioning and quality of life. In addition, longitudinal studies are needed to help determine whether pain

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predicts poorer functioning or in turn, whether poorer functioning results in increased pain and IBD symptoms. Replication of this study with patients experiencing clinically significant levels of depression and anxiety also would be useful, as the majority of participants in this study experienced subclinical levels of emotional distress. Finally, inclusion of laboratory data (e.g., CRP, lactoferrin, calprotectin), which was not available at the time this study was conducted, would be helpful to provide additional objective information regarding remission and flare status. Definition of flare and remission status independent of pain (which is not possible to do using the PCDAI) also would strengthen future studies. Because the PCDAI includes a measure of abdominal pain within the total score used to define flare status, replication of this study using other measures would help to eliminate any potential bias in understanding the impact of pain reporting on emotional distress and quality of life by disease status.

In summary, we found that similar to the adult literature, discordance between patient symptoms and objective disease state is associated with increased psychological distress and decreased quality of life. The report of pain, especially when it is discordant from disease state, appears to play an important role in understanding patients' emotional functioning, disability and quality of life. Routine screening of abdominal pain, particularly for patients in a flare, is warranted, and management of abdominal pain in children and adolescents with and without active disease, may in turn, improve their emotional functioning and quality of life. In addition, it is possible that addressing and treating patients' depressive symptoms may improve their pain and functioning and should be an important adjunct part of care for children with CD. Those patients experiencing pain with a flare may be at greatest risk for psychological distress and reduced quality of life; however, patients experiencing pain in remission also may be at risk.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Source of Funding: Funded by NIH grant R01HD36069 awarded to Dr. Levy.

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What is known

- Patients with CD experience pain and symptoms that may not coincide with disease state.
- For adults, discordance between patient and physician perceptions of physical health is associated with more negative psychosocial outcomes.
- Minimal data are available for pediatric patients.

What is new

- Pediatric patients experiencing pain in remission experienced significantly greater psychological distress compared to their pain-free counterparts.
- For patients in a flare, those with pain experienced significantly higher levels of depressive symptoms and disability and decreased quality of life as compared to those without pain.

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Table 1

Categorization of sample by pain and disease state.

	Pain	No Pain
Remission	n = 17, 14.7%	n = 63, 54.3%
Flare	n = 15, 12.9%	n = 21, 18.1%

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Table 2

Paris Classification data for study participants.

	Frequency (percentage)
Age	
A1a 0 - < 10 years	28 (24.1%)
A1b 10 - <17 years	79 (68.1%)
A2 17-18 years	2 (1.7%)
Missing	(6.0%)
Location	
L1 Distal Ileum	31 (29.5%)
L2 Colonic	15 (12.9%)
L3 Ileocolonic	45 (38.8%)
L4a Upper disease proximal to Ligament of Treitz	9 (7.8%)
L4b Upper disese distal to ligament of Treitz and proximal to distal 1/3 ileum	4 (3.4%)
Unknown	1 (0.9%)
Missing	11 (9.5%)
Behavior	
B1 Non structuring, nonpenetrating	85 (73.3%)
B2 Stricturing	9 (7.8%)
B3 Penetrating	1 (.9%)
B2B3: both penetrating and structuring	5 (4.3%)
P: perinal disease modifier	4 (3.4%)
B1 and P	1 (0.9%)
B2 and P	1 (0.9%)
Missing	10 (8.6%)
Growth	
G0 No growth delay	65 (56.0%)
G1 Growth delay	41 (35.3%)
Unknown	3 (2.4%)
Missing	(6.0%)

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Table 3

Variable means and standard deviations by disease state (remission vs. flare) and pain (present vs. absent)

	F	p	Remission No Pain (n = 63)	Remission Pain (n = 17)	Flare No Pain (n = 21)	Flare Pain (n = 15)
Functional Disability	16.45	.001	2.97 (3.79)[a]	10.65 (9.55)[b,c]	6.76 (5.59)[a,b]	14.20 (10.30)[c]
Depression	7.23	.001	5.82 (5.89)[a]	9.80 (8.21)[a,b]	6.02 (4.53) [a]	13.95 (9.17)[b]
Anxiety	3.42	.02	38.10 (15.19)[a]	42.65 (16.83)[a,b]	44.67 (13.47)[a,b]	51.78 (18.96)[b]
Quality of Life	18.81	.001	85.72 (9.93)[a]	72.85 (14.83)[b]	79.41 (11852)[a,b]	61.60 (15.62)
Other IBD symptoms	13.82	.001	.24 (.34)[a]	.65 (.60)[b,c]	.33 (.25)[a,b]	.87 (.44)[c]

Note. Within rows, means with different subscripts differ significantly at p<.05.