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Oral Medication Adherence and Disease Severity in Pediatric Inflammatory Bowel Disease

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Abstract

Objective—The purpose of this study was to examine the relationship of oral medication adherence and perceived adherence barriers with disease severity in a sample of adolescents with IBD.

Methods—Participants included 62 adolescents, aged 13–17 years, diagnosed with IBD and their parents. Measures of parent- and patient-rated oral medication adherence and related barriers, behavioral and emotional functioning per parent- and self-report, and disease severity per physician reported medical chart data were obtained.

Results—Fifteen percent of the sample reported clinically elevated depressive symptoms and 24% reported clinically elevated internalizing behavioral problems. Number of reported adherence barriers was 2.6 ± 1.5 , and no participants reported zero barriers. Parental ratings of medication adherence ($t = -2.11$, $p < .05$) and perceived barriers to adherence ($t = 2.05$, $p < .05$) significantly predicted disease severity after statistically controlling for the contributions of behavioral and disease parameters to disease severity.

Conclusions—Results suggest that oral medication adherence and perceived adherence barriers are significantly related to disease severity in adolescents with IBD. These patients also may be at risk for increased behavioral and emotional problems which may impact health outcomes as well. Clinicians should make particular efforts to attend to medication adherence issues with their patients. Working with patients and families to develop solutions for eliminating adherence barriers might result in better disease outcomes.

Keywords

Adherence; disease severity; inflammatory bowel disease; behavior; Barriers; Crohn's disease; Ulcerative colitis

Introduction

Adherence to oral medications is a substantial challenge in pediatric populations. Estimates of the prevalence of nonadherence in pediatrics is approximately 50% for children ¹ and 65–75% in adolescents ². Prior studies in pediatric Crohn's disease (CD) and ulcerative colitis (UC), collectively inflammatory bowel disease (IBD), have revealed nonadherence prevalence rates ranging from 50% ^{3–4} to 88% ⁵ across medications. Moreover, approximately 40–50% of immunomodulator and aminosalicylate doses are missed by patients ⁵.

IBD poses unique challenges to patients and families with respect to oral medication adherence. Many patients are on multiple medications with varying dosing regimens (i.e., number of doses per day, number of medications per dose). Rates of achieving therapeutic dosing levels with medications also vary. In addition, the hallmark characteristics of IBD including intermittent periods of disease activity and remission, unpredictable disease exacerbations, and the necessity for chronic treatment present additional challenges to families and providers who wish to promote adequate adherence ⁶. However, there is surprisingly limited empirical data regarding relationship of adherence and related factors (e.g., barriers to treatment adherence) with clinical outcomes such as disease severity in IBD. Kane and colleagues⁷ examined the relationship between nonadherence and relapse in a sample of adults with quiescent ulcerative colitis. They found that patients who were nonadherent, based on pharmacy refill data, were 5.5 times more likely to experience relapse. Thus, there is evidence that nonadherence in adults with UC results in poorer clinical outcomes; yet this has not been examined in pediatric IBD, in which adherence is more complex due to developmental changes in patients and shared responsibility for adhering to medications among patients and their families. Although adequate adherence in pediatric IBD is generally thought to result in better outcomes, clinicians are left with only anecdotal evidence of this relationship based on their experience, which varies across providers. The absence of empirical data linking adherence and perceived adherence barriers to disease severity highlights a substantial gap in the current literature on self-management in pediatric IBD.

Therefore, the purpose of this study was to examine the relationship of oral medication adherence and perceived adherence barriers with disease severity in a sample of adolescents with IBD. Several factors were considered when selecting variables to examine in addition to oral medication adherence. Perceived barriers have been associated with poorer adherence in other pediatric populations ^{8–9} as well as in IBD ^{10–11}. Additionally, behavioral/emotional dysfunction (e.g., symptoms of depression and anxiety, oppositional behavior, etc.) has been associated with nonadherence in pediatric populations ^{1, 12–16}. Thus behavioral/emotional factors were examined as potential predictors of disease severity in addition to adherence-related factors. Due to the high prevalence and frequency of nonadherence in IBD, and prior research demonstrating the relationship between greater perceived barriers and nonadherence, it was hypothesized that oral medication adherence and perceived barriers would each contribute significant variance to disease severity after statistically controlling relevant demographic, disease, and behavioral/emotional variables.

Methods

Participants and Procedures

Participants were recruited from two pediatric IBD centers in the northeastern and midwestern United States. Adolescent patients with IBD between 13–17 years old who were prescribed 6-mercaptopurine (6-MP)/azathioprine and/or a 5-aminosalicylic acid (5-ASA) medication and their parents were targeted for recruitment. Exclusion criteria were 1) patient

diagnosis of a comorbid chronic illness or neurocognitive disorder, 2) current regimen including greater than 1 mg/kg/day of corticosteroids, and 3) lack of English fluency in patient and parent. Potential participants were identified via chart review and recruited in person during clinic appointments or via telephone. Of the 106 patients that were eligible for participation, 83 were able to be contacted, 13 declined participation (reasons included not wanting blood draw, not enough time, and not interested in participating in research generally), and 8 did not provide complete data. Thus, the final sample consisted of 62 adolescents (35 male, 27 female) with IBD (CD $n = 49$; UC $n = 13$) and their parents. Patients with CD and UC were combined in this study, consistent with prior studies on adherence in IBD^{3, 5}, due to similarities between the conditions in medication regimens, symptom presentation, and patterns of disease activity over time. Informed consent and assent were obtained from parents and patients, respectively. Disease severity assessments were completed by study personnel using data obtained from gastroenterologists' documentation and laboratory values for the clinic appointment corresponding to the study visit or the most recent clinic appointment. Families were compensated \$25 for participation. The hospitals' Institutional Review Boards approved this study.

Measures

Medical Adherence Measure (MAM)—The MAM¹⁷ is a semi-structured interview that assesses self-management factors including medication knowledge, treatment adherence, organizational systems (e.g., where medication is kept), and perceived barriers to treatment adherence (e.g., interferes with activity, difficulty swallowing pills, hate the taste, just forget, not feeling well, does not like the side effects, not home, did not refill prescription, refuse to take medication, cannot afford, do not think it is necessary). Included in this measure are single-item, patient- and parent-reported assessments of medication adherence on a 0- (usually miss) to 10- (rarely miss) point likert scale, which simulates a typical brief clinic-based assessment of adherence by providers. Research personnel administered the measure jointly to patients and parents. The MAM has demonstrated adequate reliability and validity in other pediatric populations¹⁷.

Pediatric Crohn's Disease Activity Index (PCDAI)—The PCDAI¹⁸, is a well validated Crohn's disease severity assessment that assesses disease activity via subjective (e.g., pain) and objective criteria (e.g., physical exam), laboratory findings, and growth parameters. The total score ranges 0 – 100, with higher scores indicating more severe disease. Scores ≤ 10 = inactive disease; 11–29 = mild disease, and ≥ 30 = moderate to severe disease activity¹⁹.

Lichtiger Colitis Activity Index (LCAI)—The LCAI²⁰, is a measure of disease severity in ulcerative colitis that uses both subjective and objective criteria to assess 8 UC symptoms including daily stool frequency, nocturnal diarrhea, visible blood in stool, fecal incontinence, abdominal pain or cramping, general well-being, abdominal tenderness, and need for anti-diarrheal medication. Scores range from 0 to 21 with higher scores indicating more active disease (i.e., ≤ 2 indicate quiescent disease; 3–9 indicate a response to therapy; ≥ 10 indicate active disease and no response to therapy)²¹.

Child Behavior Checklist (CBCL)—The CBCL²² is a widely used empirically validated and reliable 113-item measure of child behavioral functioning and psychosocial distress that is completed by parents. Respondents rate the frequency of specific behaviors in their child during the previous 6 months. The CBCL yields 8 factors (Aggressive Behavior, Anxious/Depressed, Attention Problems, Rule-Breaking Behavior, Social Problems, Somatic Complaints, Thought Problems, and Withdrawal/Depressed), as well as 2 broad measures of

distress: internalizing problems (e.g., anxiety, depression) and externalizing problems (e.g., aggression, oppositional behavior).

Youth Self-Report (YSR)—The YSR is the child-report version of the CBCL. Consistent with the CBCL, the YSR also rates the frequency of specific behaviors during the previous 6 months and yields the same 8 factors and 2 broad measures of distress as the CBCL. The CBCL and YSR scores are standardized T scores and the clinical range on the Internalizing and Externalizing Problem scores are $T \geq 64$.

Children's Depression Inventory (CDI)—The CDI²³ is a 27-item self-report measure used to assess depressive symptoms in children. Each item is a group of three statements on a 0 to 2 scale that measures the severity of a depressive symptom, with higher scores, ranging from 0–54, indicating greater depressive symptomatology. The CDI is a widely used reliable and valid measure of depressive symptoms in children. Scores ≥ 13 on the CDI are considered within the clinical range.

Data Analyses

Descriptive statistics (means, standard deviations, frequencies) were conducted across disease, demographic, and behavioral variables. Independent samples t-tests were conducted to test for significant differences in disease severity as a function of participant gender or diagnosis (Crohn's disease vs. ulcerative colitis). Bivariate Pearson correlations were used to test for significant relationships among disease severity, behavioral, disease related, and demographic variables. Variables significantly correlated with disease severity were used as covariates in a simultaneous linear multiple regression model constructed to examine predictors of disease severity. Because higher values on both disease activity measures represented greater severity, both measures were continuous, and regression analyses were used to examine the hypotheses, PCDAI and LCAI scores were collapsed across participants to form a separate continuous variable representing disease severity. Each original score remained unchanged; however, the new variable allowed for the appropriate analysis without dividing the sample based on IBD subtype. Adherence and disease-severity measures were treated as continuous variables for analyses. All analyses were conducted in PASW 17.0 for Windows.

Results

Descriptive Analyses

Demographic data are presented in Table 1. Depression severity reported on the CDI was in the subclinical range (5.85 ± 6.43) overall; however, 15% of the sample reported clinically elevated depressive symptoms. Internalizing Problem scores on the CBCL were 53.11 ± 12.02 , with 24% of the sample in the clinical range; Externalizing Problem scores were 45.81 ± 10.11 , with 6% in the clinical range. Internalizing Problem scores on the YSR were 51.73 ± 10.64 , with 18% of the sample in the clinical range; Externalizing Problem scores were 47.39 ± 8.80 , with 0% in the clinical range. Adherence ratings were similar across patients (8.5 ± 1.3) and parents (8.9 ± 1.1). Number of reported barriers ranged from 1–7, with a mean of 2.6 ± 1.5 , and none of the participants reported zero barriers to adherence. Table 2 illustrates the distribution of reported adherence barriers. Mean disease severity on the PCDAI in this sample was 11.68 ± 10.02 , with 55% classified as inactive, 37% as mild, and 8% as moderate to severe. The measure has demonstrated good sensitivity and specificity^{18–19}. Mean disease severity on the LCAI in this sample was 2.85 ± 3.87 , with 61% classified as quiescent, 31% as responding to therapy, and 8% as active disease and no response to therapy.

Selection of Covariates

Independent samples t-tests revealed a significant difference in disease severity between patients with CD vs. UC ($p < .01$). No difference in disease severity was observed between males and females. Bivariate correlation analyses revealed significant correlations between disease severity and parent-rated adherence ($r = -.34$, $p < .05$), patient-rated adherence ($r = -.29$, $p < .05$), adherence barriers ($r = .32$, $p < .05$), depressive symptoms ($r = .26$, $p < .05$), and YSR Internalizing Problems ($r = .25$, $p < .05$).

Regression Analysis

In order to examine the primary hypothesis, a multiple regression model was constructed in which disease severity was entered as the dependent variable and all covariates (i.e., IBD Diagnosis, CDI Total Score, YSR Internalizing Problems T Score, Patient Adherence Rating, Parent Adherence Rating, Perceived Barriers to Adherence) were entered simultaneously. Simultaneous entry of covariates was preferred to examine the relative beta weights of each variable in a single step of the regression. This overall model was significant ($R^2 = .35$, $p < .01$), and parental ratings of medication adherence ($p < .05$) and perceived barriers to adherence ($p < .05$) emerged as significant predictors of disease severity after the contributions of behavioral and disease parameters to variance in disease severity were statistically controlled.

Discussion

This is the first study to examine the relationship between oral medication adherence and disease severity in a pediatric sample of IBD patients. Results demonstrated that parental ratings of medication adherence and perceived barriers to adherence reported on the MAM both emerged as independent predictors of disease severity after statistically controlling for behavioral/emotional variables and type of IBD diagnosis. Although the link between medication adherence and disease severity is intuitive and supported by anecdotal evidence and case reports²⁴, this study presents novel empirical evidence of this relationship. The observed relationship between perceived barriers and disease severity is complex. Certain barriers are likely to have a direct impact on disease severity (e.g., oppositional behavior with taking medications, forgetting to refill prescriptions, illness resulting in decreased desire to consume medications, etc.), while others are indirectly related to disease severity (e.g., interference with activities, forgetting to take medications, etc.). Thus, with greater number of perceived barriers, there is increased likelihood that barriers exerting a direct influence on disease severity are present. Unfortunately, the sample size of this study precluded statistical probing of this relationship among the variables. However, assessment of specific barriers that impact disease severity directly and indirectly should be a focus of future investigation. Taken together, the present findings suggest that clinicians should make particular efforts to attend to medication adherence issues with their patients. Inquiring about patterns of missed doses and the types of barriers that patients are experiencing that lead to nonadherence can provide invaluable insight into patient self-management behavior. Additionally, providing assistance to patients and families via problem solving around barriers might result in better disease outcomes, particularly with respect to disease activity.

Other salient findings that emerged from this study include the increased incidence of clinically significant internalizing behavioral problems, particularly depression, relative to the normative reference data from the CBCL/YSR and CDI measures^{22–23} which is consistent with rates in other chronic illness conditions²⁵. This is an important, yet often neglected area of health care that has the potential to negatively impact health outcomes in this pediatric population{Sewitch, 2001 #364}. As such, incorporating psychological screening measures would be beneficial to identify patients who are experiencing

behavioral/emotional difficulties. Additionally, the mean number of barriers to adherence reported by participants was approximately three, and all participants reported experiencing at least one barrier. This suggests that there is substantial work to be done in the area of self-management promotion in pediatric IBD. It would likely be beneficial for clinicians to devote time during clinic visits to assess the presence and impact of adherence barriers in their patients. If this is impacting treatment progress, working with patients and families to develop solutions for eliminating those barriers would be particularly important. Further, a referral to a pediatric psychologist might be necessary to assist with difficult behavior changes.

The significance of these findings must be taken within the context of a few limitations. First, the majority of families in this study represented upper middle socioeconomic class with a high percentage of married parents, high parental employment and college education, and high annual income. Although this is consistent with prior research in pediatric IBD^{26–28}, generalization to patients and families from lower socioeconomic backgrounds should be made with caution. Indeed, socioeconomic factors may impact variance in disease severity directly, but we were unable to test this with limited sample size and variance in socioeconomic status of participants. Second, patients in this study had quiescent to mild disease severity. Because patients were recruited during or shortly after outpatient clinic appointments and not during inpatient admissions, disease severity was likely milder than it might have been if patients were recruited while hospitalized. Consequently, these findings may not generalize well to periods during which patients are experiencing significant disease exacerbations. It may be that, while adherence is a salient predictor of disease severity in mild IBD, other factors (e.g., environmental exposure to viral or bacterial infection) could account for more variance in disease severity during acute exacerbations. Third, data collection began prior to the publication of the Pediatric Ulcerative Colitis Activity Index²⁹. Thus, the disease severity measure for ulcerative colitis patients in this study may not be the most rigorously validated measure. Fourth, a heterogeneous sample of IBD patients and two types of medications were examined in this study. Thus, the independent contribution of nonadherence to specific medications on IBD subtype will be an important next step in this area of research. Fifth, the use of self- and parent-rated adherence may have resulted in overestimates of adherence{Rapoff, 2010 #695}. While no measure of adherence actually confirms number of pills ingested, more sophisticated measurement such as electronic monitors might provide the most proximal measure for this purpose. Finally, this study was correlational in nature. Thus, while treatment adherence and adherence barriers are significantly associated with disease severity, the directionality and causal nature of this relationship remains an empirical question.

Future research should focus on examination of the causal influence of nonadherence and quantity and type of adherence barriers on disease severity in both Crohn's disease and ulcerative colitis samples. In addition, other self-management parameters, including dietary management, stress and pain management, and clinic appointment adherence should be examined as factors related to disease severity. Other salient disease outcomes including health care utilization, frequency of hospitalization, and surgery should also be examined in relation to self-management. Finally, randomized controlled trials examining the effect of behavioral treatment of nonadherence on disease outcomes is a critical need in this population. Our current clinical trial research is addressing these issues and results are forthcoming. It is anticipated that clinical attention to patient and family factors contributing to poor self-management will enhance health care delivery and substantially improve disease outcomes in IBD.

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Table 1

Demographic and disease-related descriptive data.

	%	M ± SD
Adolescent age (years)		15.47 ± 1.41
Gender (% male)	56.4%	
Ethnicity (% White, not Hispanic origin)	88.7%	
Primary caregiver marital status (% married)	88.7%	
Primary caregiver education level (% with at least some college education)	50%	
Primary caregiver employment status (% employed)	86.3%	
IBD Diagnosis (%)		
Crohn's Disease	79.0%	
Ulcerative Colitis	21.0%	
Median annual family income = \$75,001 – \$100,000		

Table 2

Distribution of reported adherence barriers.

Barrier	Crohn's Disease (n = 49)		Ulcerative Colitis (n = 13)		Total (n = 62)	
	n	%	n	%	n	%
Don't miss	0	0	1	7.7%	1	1.6%
Interferes with activity	20	40.8%	4	30.8%	24	38.7%
Hard to swallow pills	6	12.2%	0	0	6	9.7%
Hate the taste	8	16.3%	0	0	8	12.9%
Just forget	42	85.7%	11	84.6%	53	85.5%
Not feeling well	8	16.3%	1	7.7%	9	14.5%
Don't like the side-effects	4	8.2%	0	0	4	6.5%
Wasn't home	22	44.9%	5	38.5%	27	43.5%
Ran out/didn't fill	7	14.3%	2	15.4%	9	14.5%
Refuse to/defiant	6	12.2%	1	7.7%	7	11.3%
Can't afford	0	0	0	0	0	0
Don't think necessary	8	16.3%	0	0	8	12.9%
Other	8	16.3%	4	30.8%	12	19.4%