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Concordant parent-child reports of anxiety predict impairment in youth with functional abdominal pain

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Abstract

Introduction—Functional abdominal pain (FAP) is associated with significant anxiety and impairment. Prior investigations of child anxiety in youth with FAP are generally limited by small sample sizes, based on child report, and use lengthy diagnostic tools. It is unknown 1) if a brief anxiety screening tool is feasible, 2) whether parent and child reports of anxiety are congruent, and 3) whether parent and child agreement of child anxiety corresponds to increased impairment. The purpose of this investigation was to examine anxiety characteristics in youth with FAP using parent and child reports. Parent-child agreement of child anxiety symptoms was examined in relation to pain and disability.

Materials and Methods—One-hundred patients with FAP (8-18 years of age) recruited from pediatric gastroenterology clinics completed measures of pain intensity (Numeric Rating Scale), and disability (Functional Disability Inventory). Patients and caregivers both completed a measure of child anxiety characteristics (Screen for Child Anxiety and Related Disorders).

Results—Clinically significant anxiety symptoms were more commonly reported by youth (54%) than their parents (30%). Panic/somatic symptoms, generalized anxiety, and separation anxiety were most commonly endorsed by patients whereas generalized anxiety, separation anxiety, and school avoidance were most commonly reported by parents. The majority (65%) of parents and children agreed on presence (26%) or absence (39%) of clinically significant anxiety. Parent-child agreement of clinically significant anxiety was related to increased impairment.

Discussion—A brief screening instrument of parent and child reports of anxiety can provide clinically relevant information for comprehensive treatment planning in children with FAP.

Functional abdominal pain (FAP) is a common problem impacting 12% of youth in the general population (1). FAP accounts for approximately 5% of all referrals to primary care providers, and is associated with costly, unnecessary and potentially risky medical procedures (2). Youth with FAP who present to pediatric gastroenterology clinics experience significant pain symptoms and increased disability including school avoidance, social problems (i.e., peer victimization), and psychological symptoms (e.g., anxiety, depression) (3-5). For 25% to 45% of youth with FAP, pain symptoms persist for many years (6, 7), with some individuals developing additional pain conditions such as headaches (6) or other somatic complaints (7). Academic problems, social difficulties and school absences in particular are reported for many of these youth (6, 8). Findings from well-designed longitudinal studies have suggested that co-morbid anxiety could be an important factor in predicting long-term problems with unremitting pain symptoms and disability in youth with FAP (9-12).

Anxiety has been found to be highly prevalent in youth with FAP (13) with an estimated 42% -85% of youth with FAP seen in gastroenterology clinics meeting diagnostic criteria for an anxiety disorder, with generalized anxiety, social anxiety, and separation anxiety commonly occurring across investigations (4, 5, 12, 14). These findings are generally based on studies with relatively small sample sizes (e.g., n's 14-42). In a notable exception, Shelby and colleagues assessed psychiatric disorders in 332 children diagnosed with FAP in adolescence and young adulthood and found that anxiety disorders correspond to maintenance of abdominal pain symptoms over time (12). However, all of these aforementioned investigations employed lengthy diagnostic interviews that are cumbersome and impractical to integrate into busy medical settings. Although structured clinical interviews remain the gold standard for psychological diagnosis, a brief clinical screening tool which could incorporate both parent and child reports of anxiety symptoms would allow for rapid detection of clinically significant psychological symptoms that may indicate the need for psychological care.

Past studies have found a strong link between self-reported child anxiety levels and functional disability among children with FAP (10, 11), but there has not been any research thus far examining whether parent/caregiver and child reports of clinically significant anxiety are congruent and whether or not concordance of parent-child reports relates to pain and impairment in youth with FAP. In the broader pediatric pain literature, there is evidence to suggest that the majority (>70%) of parent-child reports of pain catastrophizing (i.e., a tendency to overestimate the poorest outcomes associated with pain, which is characteristic of anxiety) are *concordant* (15). Moreover, when parent-child reports are discordant, impairment is more strongly related to the child's report of high catastrophizing. The current investigation assessed both child reported anxiety and parent perception of their child's anxiety. Given the impact of child anxiety on outcomes in youth with FAP, understanding of parent perception of child anxiety is critical given that parents initiate clinical care for such youth. At present, it is unknown if parent and child reports of child anxiety are congruent in

this population, and if parent-child agreement of child anxiety symptoms is related to increased pain and impairment in youth with FAP specifically.

The aims of the current investigation were to 1) study the prevalence of clinically significant anxiety and anxiety characteristics in patients with FAP who present to a pediatric gastroenterology clinic using a brief anxiety screener (Screen for Child Anxiety and Related Disorders; (16)) based on parent and child report, 2) assess whether clinically significant child anxiety was associated with higher pain and pain-related disability, 3) examine the concordance of parent and child reports of whether or not the child has clinically significant anxiety, and 4) explore the impact of concordant versus discordant reports of child anxiety on pain and functional disability outcomes. Based on prior investigations, we predicted that generalized anxiety, separation anxiety, and social anxiety would be the most common anxiety subtypes in youth with FAP. Consistent with previous investigations (10, 11), we also predicted that FAP patients who fell in the clinical range of severity for anxiety symptoms on the screening measure would show significantly higher levels of pain and pain-related impairment than those who did not. We predicted relatively high parent-child concordance on reports of presence or absence of clinically significant anxiety symptoms (>70%) based on findings from a study of parent and child reports of catastrophizing in a broad pediatric pain sample (15). Finally, we explored whether parent-child agreement of reports of clinically significant anxiety were related to pain and disability associated with pain but did not make specific hypotheses given the paucity of prior research in youth with FAP.

Materials and Methods

Participants

Participants were youth ($n = 100$) with FAP and their primary caregiver presenting to one of three pediatric gastroenterology clinics at a large Midwest children's hospital between February 2012 and May 2014. Inclusion criteria were: 1) patients between the ages of 8 and 18, 2) patient and caregiver ability to read and comprehend written English and 3) diagnosis of FAP by the pediatric gastroenterologist. Based on Rome-III criteria for children and adolescents, FAP denotes abdominal pain symptoms without an organic cause identified (15) and for the purposes of our study included at least 3 episodes of abdominal pain that occurred during the past three months and caused significant interference in daily activities (9). In some cases, FAP subtypes (e.g., irritable bowel syndrome, abdominal migraine, functional dyspepsia) were assigned by physicians guided by Rome-III criteria, but were not stringently based on these criteria, which is consistent with clinical practice in other samples of pediatric FAP (17). Patients were ineligible for the study if 1) they had a significant medical condition(s) with an identifiable organic cause (e.g., inflammatory bowel diseases such as Ulcerative Colitis and Crohn's Disease, Sickle Cell, Cancer), 2) abdominal pain was a potential symptom or side effect of treatment or 3) patients had significant developmental delays or cognitive impairments.

Procedures

Patients and their families were invited to participate in a research study during their medical visit at a pediatric gastroenterology clinic. If agreeable, written consent from the parent/primary caregiver and assent from the child were obtained by research staff prior to completion of any measure. Patients and their parent then completed a battery of measures as a part of an Institutional Review Board (IRB) approved protocol aimed at investigating psychosocial factors impacting impairment in youth with FAP.

Measures

Demographic Information—Detailed demographic and background information including race, ethnicity, age, gender, and socioeconomic status were collected from the parent.

Pain Intensity

Numeric Rating Scale (NRS) Pain Intensity – Child Report: The NRS pain rating scale assesses average pain intensity (0-10 scale) over the last two weeks, with “0” indicating no pain, and “10” reflecting worst possible pain. The NRS pain intensity scale has been validated in pediatric pain samples and is recommended for use in clinical studies of pain in school-age children (18).

Functional Disability Inventory- Child Version (FDI-C)—The FDI-C is a 15-item validated measure which assesses physical functioning and difficulty completing activities due to pain through child report (19). Responses to each item range from 0 (no trouble) to 4 (impossible), and are summed to create a total disability score. Scores range from 0-60, with 0-12 indicating no/minimal disability, 13-29 indicating moderate disability, and 30 or higher indicating severe disability (20). The internal consistency (Cronbach's alpha) estimate for the FDI in the current sample was 0.89, which is considered good.

Screen for Child Anxiety Related Disorders – Parent/Child Report (SCARED-C/P)—The SCARED is a brief (~5 minutes) and widely used screening instrument for clinically significant anxiety symptoms in youth based on DSM-IV-TR (16) subtypes of anxiety (e.g., generalized anxiety, social anxiety, separation anxiety), has been validated for use in children ages 8 and above (21, 22) and has been psychometrically validated in a pediatric pain sample (23). This measure has also been used to assess anxiety in clinical samples of youth with FAP (4, 5). Patients report frequency of anxiety symptoms over the past three months on a 41-item measure with responses including “not true” “sometimes true”, and “often true”. Total scores range from 0-82, with higher scores reflecting greater levels of anxiety. For the current study, the presence of clinically significant anxiety was defined as a clinical cut-off total score ≥ 25 , based on psychometric research indicating optimal sensitivity and specificity at this cut-off (21, 22). We also operationalized parent-child agreement of child anxiety symptoms based on this cut off (i.e., if the parent and child report of child anxiety both fell inside or outside of this cut-off, they were considered congruent). Further, anxiety subtypes based on clinical cut-offs (i.e., generalized anxiety, separation anxiety, social anxiety, panic, school avoidance) were used. Of note, the school avoidance subscale (4 items) included two items that referenced the presence of pain

symptoms (stomachaches and headaches) in a school setting. To account for potential multicollinearity, we removed these items and defined school avoidance as “present” with a score of 2 or greater out of 4 (two of two items marked as “sometimes true” or one of two items marked as “very often true”). The items used were: “I (my child) am (is) scared to go to school;” and “I (my child) worry (worries) about going to school.” Internal reliability of the SCARED was calculated with Cronbach's alpha. The reliability values for the total measure were 0.93 (child report) and 0.95 (parent report). For the subscales, the Cronbach's alpha were as follows: generalized anxiety (0.91 parent, 0.88 child), separation anxiety (0.83 parent, 0.71 child), social anxiety (0.89 parent, 0.85 child), panic (0.88 parent, 0.89 child), and school avoidance (0.76 parent, 0.83 child). All of these are in the good to excellent range except for the child report of separation anxiety and the parent report of school avoidance, which are in the acceptable range.

Statistical Analysis

Data were analyzed using SPSS 22.0. Missing data were less than 5%, which included 1 child report and 4 parent reports. In the case of missing item-level data, an unbiased estimate of the total/subscale scores was computed by calculating the mean of the available item scores, and then multiplying this value by total number of items in the scale/subscale. The result is a maximum likelihood score/subscale estimate. Descriptive data were computed for all demographic variables and measures of pain, functional disability, and anxiety. Rates of clinically significant anxiety (SCARED total score ≥ 25) and presence of anxiety subtypes, based on clinical cut-off (cc) scores for each subscale, were calculated based on child and parent report. We conducted Fisher's exact tests to examine whether differences in child and parent reported anxiety were statistically significant using a Bonferroni correction ($p < 0.05/5 = p < 0.01$). Next, we conducted multivariate analyses of covariance (MANCOVA) to compare outcomes (pain intensity and functional disability levels) in youth based on presence of clinically significant anxiety (separate analyses for parent and child reports of anxiety) when controlling for age (see pain characteristics subheading in the Results for justification of including age as a covariate).

For our exploratory analyses, we examined the concordance of parent and child reports of clinically significant child anxiety. Concordance was established by agreement in endorsement of clinically significant anxiety symptoms (clinical cut-off total score ≥ 25). Based on these data, multivariate analyses of variance (MANOVA) was performed to investigate differences in pain and impairment based on parent-child agreement/disagreement of child anxiety. Bonferroni corrected post hoc testing was completed to assess for significant differences between the groups.

Results

Patient characteristics

A total of 117 families were approached, with 17 families declining to participate (>85% participant agreement overall). The sample consisted of 100 patients (ages 8 to 18, mean (m) age=13.03, SD=3.14) seen in a pediatric gastroenterology clinic and diagnosed with FAP. The majority of the patients were female (73%) and Caucasian (87%; see Table 1 for

additional sociodemographic information). This patient profile parallels those reported in prior studies of youth with FAP (24). Parent informants were primarily mothers (83%).

Pain characteristics

The majority of patients reported a pain duration for one year or longer (74%). In terms of FAP diagnoses, the largest proportion of youth was classified with functional abdominal pain without a specific subtype diagnosis (51%). On average, patients reported moderate levels of pain ($m = 4.22/10$, $SD = 2.08$) and moderate disability ($m = 14.10$, $SD = 9.79$). Patient age, pain duration and gender were not significantly associated with study outcome variables of functional disability (all test values n.s.) or pain severity with one exception: older patients had higher pain intensity scores ($r = 0.20$, $p < 0.05$). Thus, we controlled for age when examining pain severity as a dependent variable in our primary analyses.

Anxiety in youth with FAP

High rates of global anxiety in youth with FAP were noted, with 54% of patients reporting clinically significant anxiety (See Table 2). Parent report measures yielded uniformly lower rates of clinically significant anxiety (rate of 30%). The most common anxiety subtypes based on child report were panic/somatic symptoms (44%), generalized anxiety (43%), separation anxiety (42%), whereas by parent-report, the most common types of anxiety included generalized anxiety (34%), separation anxiety (26%), and school avoidance (22%). With the exception of social anxiety, Fisher's exact tests revealed that parent and child reports of global anxiety and the anxiety subscales were significantly different from one another, with children consistently reporting higher levels of anxiety (See Table 2 for additional information).

Child-reported anxiety in relation to child reported pain and disability

Multivariate analysis of covariance revealed a significant difference in average pain scores for those children who reported clinically significant anxiety ($m=4.74$, $SD=1.98$) versus those without elevated anxiety ($m = 3.60$, $SD = 2.07$) after controlling for age ($F(1, 96) = 7.38$, $p < 0.01$). There was also a significant difference ($F(1, 96) = 10.97$, $p < 0.01$) in self-reported disability levels for those with clinically significant anxiety ($m=17.07$, $SD = 9.58$) versus those without elevated anxiety ($m = 10.71$, $SD = 9.00$).

Parent-reported anxiety in relation to child reported pain and disability

After controlling for age, there was a significant difference in average pain for those with clinically significant anxiety via parent report ($m=4.97$, $SD=1.97$) versus those without elevated anxiety ($m = 3.89$, $SD = 2.10$; $F(1, 93) = 6.22$, $p < 0.05$). There was also a significant difference in disability levels for those with parent-reported clinically significant anxiety ($m=17.17$, $SD = 10.55$) versus those without elevated anxiety ($m = 12.97$, $SD = 9.30$; $F(1, 93) = 4.27$, $p < 0.05$).

Parent-child agreement of anxiety symptoms

The majority (65%) of parents and children agreed on (26%) presence or absence (39%) of clinically significant child anxiety symptoms. Among the discordant reports, 27% of patients

reported clinically significant anxiety whereas their caregiver did not and only 4% of patients reported subclinical levels of anxiety with parents reporting clinically significant child anxiety.

Informant agreement of anxiety in relation to pain and disability

Based on the aforementioned findings, the groups tested in the MANOVA were as follows: 1) both parent and child reporting clinically significant level of child anxiety ($n = 26$, “concordant high”); 2) both parent and child reporting subclinical levels of child anxiety ($n = 39$, “concordant low”) and 3) child reporting clinically significant child anxiety with parent reporting subclinical levels of child anxiety ($n = 27$, “discordant”). Only 4 dyads reported clinically significant child anxiety based on parent report and subclinical anxiety based on child self-report; thus, these dyads were not included in analyses. Two dependent variables were used: child reported pain and child reported pain-related disability. There was a statistically significant difference between groups on the outcome variables, $F(2, 89) = 2.05$, $p < 0.05$. Bonferroni-corrected post hoc analyses revealed that the group of children and parents who agreed on high child anxiety (“concordant high” group) evidenced increased child-reported pain and disability as compared with those parent-child reports corroborating subclinical levels of child anxiety (“concordant low” group; See Table 3 for additional details). In the discordant group, the child-reported pain and disability scores fell in between the two concordant groups though the scores were not statistically different from either concordant group.

Discussion

This study demonstrated that a relatively brief multi-informant screening instrument for assessment of anxiety can readily be incorporated into medical clinics and provides important information from both the patient and caregiver (parent) perspectives about the presence of clinically significant anxiety symptoms, anxiety subtypes and the impact of anxiety on pain and disability in youth with FAP.

We found high rates of clinically significant anxiety *symptoms* (54%) in patients with FAP that are comparable to published rates of anxiety disorders in youth with FAP based on more intensive structured clinical interviews (4, 5, 12, 14). It is noteworthy that children reported higher global levels of clinically significant anxiety in themselves compared to parent reports of their child's anxiety on average (54% vs. 30% in our sample). This finding is consistent with clinical data suggesting that children generally report higher levels of psychological distress in themselves as compared to other informants (25), possibly because children are more attuned to their own internal cognitive and somatic symptoms (i.e., anxious thoughts) that may not be obvious to observers, including their parents. In cases where anxiety symptoms are not identified by parents, these symptoms may also be less likely to be observable to other providers (e.g., medical professionals, teachers). As a result, such youth may not be identified in a timely fashion, and may therefore not be referred for additional care, such as training in behavioral pain coping skills, which has been shown to be effective in the management of pain and disability in youth with chronic pain (26-28) or for evidence-based behavioral interventions for anxiety management (29).

Overall, parents and children generally agreed on reports of child anxiety symptoms (65% agreement) which is comparable to the hypothesized agreement rate of >70%. Importantly, we also found that parent-child agreement of presence of clinically significant anxiety symptoms is associated with increased pain and impairment. Thus, by administering an anxiety screener to parents and children, clinicians can quickly interpret results and readily identify those youth who might be at greatest risk of pain and impairment (i.e., those with parents and children who both report clinically significant levels of child anxiety). In such a case, physicians can begin to educate the family about how a shared parent-child report of the child's elevated anxiety levels may correspond to increased pain and disability. For such families, it may be especially beneficial to include behavioral intervention for pain coping and anxiety management into the treatment plan.

The findings from this study also showed that when there is parent-child *disagreement* regarding child anxiety symptoms, specifically when children report clinically significant levels of anxiety in themselves that is not observed by parents, their outcomes are not significantly different than the parent-child dyads who agree on levels of child anxiety. This discordant group seemingly falls in between the other two concordant groups in terms of pain and impairment. For these families, a discussion about the discrepancy and alerting the parent about the child's anxiety and the role of child anxiety in relation to the child pain experience may a helpful method of tailoring behavioral interventions based on the child's presenting concerns.

Findings from this study also provide a more in depth understanding of the typical profile of youth with FAP with regards to co-occurring anxiety symptoms. Of all of the anxiety subtypes, it is noteworthy that children reported highest levels of panic/somatic symptoms. Although high levels of panic/somatic symptoms reported by patients was not corroborated with parent report, this discrepancy may be because children may experience somatic symptoms that are not externally observable but occur while enduring significant distress. Both parents and children reported elevated levels of generalized anxiety, separation anxiety and school avoidance in youth with FAP. Clinically, this may manifest itself in youth who present with pain and show anxious behaviors around separating from caregivers, attending school, and experiencing distressing somatic symptoms which they may not always overtly express. It is also noteworthy that other types of anxiety, such as social anxiety, were less commonly reported by youth with FAP and their caregivers.

The differences in functioning between patients who have clinically significant levels of comorbid anxiety versus those who do not is striking. Youth with comorbid FAP and anxiety reported disability levels that were almost twice as high as those who did not meet clinical cut-offs for anxiety. Similarly, pain levels were higher in patients who had clinically significant anxiety. A child with FAP who shows moderate levels of disability may have a great deal of trouble participating in social and daily activities (i.e., being in school day, doing things with friends). Thus, it is especially important to identify significant anxiety symptoms in youth with FAP because the consequence of these symptoms on their pain and impairment is substantial and is likely to complicate of the course of treatment and prolong recovery.

A few limitations of this study should be noted. First, this study was cross-sectional and collected during a single visit to a pediatric gastroenterology visit. Thus, longitudinal research that builds on prior work examining long-term functioning in youth with FAP (30) is needed to *specifically* examine the impact of anxiety in predicting future pain and disability. Additionally, evaluation of other psychological problems, such as depressive symptoms, may also be beneficial as depressive symptoms have also been shown to co-occur in youth with FAP (12). This may be important because additional psychological comorbidities may indicate a clinically complex patient that warrants even greater levels of care (e.g., referral to psychiatry for medication management, comprehensive outpatient therapy with a pediatric psychologist) as compared to patients with anxiety only who may be amenable to a brief intervention. Furthermore, the majority of the sample was Caucasian and female, thus limiting generalizability of the findings. Another limitation was that we did not obtain parent self-report of their own anxiety, which may have an impact on parenting behaviors, to what extent they catastrophize or misinterpret their own child's anxiety, and which also may reflect an overall negativity bias in the way that they answer questions about their child.

In summary, the findings of this study suggest the importance of screening for anxiety in youth with FAP because patients with elevated anxiety, and particularly in cases where patients and parents agree, are at markedly *increased risk* for pain and impairment and may require additional behavioral interventions to reduce this risk. Furthermore, our data suggests that in many cases these patients (those who report clinically significant levels of anxiety while their parents do not) would otherwise go unrecognized without a screening assessment. While our findings suggest it is critical to primarily consider patient report of anxiety, it may be equally important to obtain parent reports as these data provide an opportunity to educate parents and other providers about the results, which may be particularly important in cases where discrepancies between parent and child report exist, given that children who self-report higher levels of anxiety may have increased pain and impairment even in the absence of parent agreement. Finally, understanding the most common symptom presentations can help clinicians to better tailor care to youth with FAP. For example, additional focus on skills to address generalized anxiety may be particularly beneficial in behavioral interventions for youth with FAP and co-occurring anxiety to improve pain and disability, although more work is needed to empirically validate tailored dual symptom interventions for specific anxiety subtypes and pain.

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Table 1
Sample Characteristics (n = 100)

	N
Gender	
Female	73
Male	27
Ethnicity	
Caucasian	87
Asian American	4
Hispanic/Latino	3
American Indian	2
African American	2
Biracial	1
Other	1
Pain Duration	
3-6 months	17
7-11 months	9
1-3 years	33
>3 years	41
Pain Diagnosis	
FAP (no subtype)	51
IBS	39
Functional Dyspepsia	6
Abdominal Migraine	4
Participating Caregiver	
Mother	83
Father	11
Grandmother	3
Aunt	3
Parent high school completion	
Mother	94
Father	81

Note. FAP = functional abdominal pain; IBS = irritable bowel syndrome.

Table 2
Anxiety characteristics based on parent and child report (n = 100)

	Child		Parent	
	M (SD)	% met cc	M (SD)	% met cc
Total (range: 0-82, cc = 25)	28.06 (15.5)	54**	20.74 (15.4)	30
Panic/Somatic (range 0-26, cc=7)	6.93 (5.9)	44*	3.72(4.4)	20
Generalized anxiety (range 0-18, cc=9)	7.63 (5.1)	43*	6.52 (5.0)	34
Separation (range 0-16, cc = 5)	4.26 (3.2)	42**	3.09 (3.5)	26
School avoidance (range: 0-4, cc = 2)	1.17 (1.3)	39**	0.80 (1.1)	22
Social (range 0-14, cc = 8)	5.70 (3.8)	35	4.67 (3.8)	18

Note. M = mean, SD = standard deviation, cc = clinical cut-off score. Fisher's exact test results =

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 p<0.001 and

*
 p<0.01

Table 3
Mean (SD) scores of child-reported functional disability and pain based on concordance of parent and child reports of anxiety

Outcomes	Concordant High (n = 26)	Discordant (n =27)	Concordant Low (n =39)
Child Report			
FDI (0-60)	18.92 (10.2) ^a	15.44(8.96)	11.26(9.3) ^b
Pain (0-10)	5.08(1.9) ^a	4.37(2.1)	3.56(2.09) ^b

Note.

^a indicates mean difference is significantly different from;

^b high=clinically significant; low = sub clinical; only 4 participants had clinically significant child anxiety per parent report and subclinical anxiety per child report, thus this subgroup was not examined.