



## Parents' Fears and Worries about Recurrent Abdominal Pain

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Abdominal pain is common in children and adults alike. As many as 9 to 25% of schoolaged children suffer from recurring episodes of moderate to severe abdominal pain (RAP)<sup>(1)</sup>.

In addition to the distress that is associated with the anticipation of pain or actual pain, increased school absence is a significant worry in these children. Spontaneous recovery is common, but many children continue to suffer even into adulthood<sup>(2-4)</sup>. Despite the risk for lifetime suffering and the effects on academic and social functioning, RAP has received relatively little attention in the medical literature in comparison to the adult functional bowel disorders.

Children, especially at younger ages, are still developing their coping skills and are, therefore, often ill-equipped to deal with functional abdominal pain. Parents - as the major caregivers -- are confronted with the difficult tasks of relieving their child's suffering and teaching better coping skills. Considering the irregularity and uncontrollability of functional abdominal pain, coping with its occurrence is a daunting task that even adults may struggle with. Because of the desire of any parent to ease their child's pain, it is understandable that many parents feel very frustrated and incapable of dealing with their child's stomachaches.

Nevertheless, some parents seem to be doing better than others. Some families feel less need for treatment and diagnosis by a physician than others do, and not every child that suffers from recurrent abdominal pain misses many days out of school. One could argue that patients with more severe pain have an increased likelihood of seeing a doctor or missing school, but this is not necessarily the case. In adults suffering from Irritable Bowel Syndrome (IBS), consulting a doctor is associated with more psychological distress independent of symptom severity<sup>(5)</sup>, and in high school students with RAP, more distress caused by pain was associated with seeing a physician<sup>(6)</sup>.

In younger children, the decision to visit a doctor or stay out of school is usually made by the parent rather than the child. Thus, parental thoughts and worries about their child's illness are of greater significance in these decisions than the child's cognitions. In fact, we have found that parents who have IBS themselves are far more likely to take their child to a doctor for gastrointestinal symptoms than parents who do not suffer from IBS<sup>(7)</sup>.

Research has shown that only a small proportion of people experiencing symptoms consult a doctor for them<sup>(8)</sup>. Reasons for going to a doctor are 'symptoms getting worse' or the fear that symptoms are caused by internal physical causes. High users of medical care perceive themselves as ill and vulnerable to illness, and believe their physician can be helpful. Low users, on the other hand, feel that they are more able to treat themselves<sup>(8)</sup>. There are no data on the specific parental fears and

worries associated with RAP, but concern about a disease is most likely an important factor. In a study among 98 mothers of children with unexplained abdominal pain, 65.3% believed physical factors were causing their children's symptoms<sup>(9)</sup>. Fear of a severe illness is also a common health belief in adult patients with IBS<sup>(10,11)</sup>.

Worry about an illness might be common, but it is unlikely to be the only belief that contributes to consulting behavior and school absences. To learn more about these beliefs, we conducted in-depth interviews with 15 parents of children with RAP (age 5 to 13 years) visiting GI clinics<sup>(12)</sup>. From these interviews, a model of parental cognitions was developed that includes the following categories:

- (a) Pain concerns, i.e., worrying about pain and the consequences of the pain (such as, missing school).
- (b) Pain threshold, i.e., children were NOT perceived as complaining very easily of pain or faking pain.
- (c) Thoughts about physicians, i.e., parents reported a desire for relief and care, plus frustration with doctors and reluctance to give medications.
- (d) Thoughts about coping, i.e. parents felt unable to cope or decide what to do and were afraid to ignore the pain.
- (e) Exacerbating factors: these included stress, eating habits and modeling (similarity to parents); and
- (f) Fear of disease, i.e., worrying that the child has cancer or a structural abnormality.

Parental cognitions about RAP revolved around the fear of disease and a desire for diagnosis and effective treatment. Many parents felt their children did not complain easily and they felt helpless to know how to deal with the child's suffering.

Having identified in a preliminary way the types of worries parents of children with RAP have, it was important to study which of these worries are associated with seeing a physician and with school absences. A 51-item questionnaire was developed on the basis of the indepth interviews: the Parental Worry of RAP Questionnaire (PWRQ)<sup>(13)</sup>. Parents of children with RAP were recruited online through the UNC Center for Functional GI & Motility Disorders web page.

The PWRQ was completed by 233 parents (child age range 3-18 years old). Internal consistency of the entire scale (Cronbach's  $\alpha = 0.83$ ) as well as the subscales was moderate to good (.62  $\alpha$  to .87), which means that the items on the scale tend to measure the same thing. All questions were easily understood, as shown by the fact that mean subject-rated understandability on a 5-point scale was between 4.22 and 4.87.



Cognitions of the 167 parents who consulted a doctor for their child's stomachaches differed significantly from the 66 parents who did not consult. Consulting parents worried more about their child's pain, were more likely to think their child might be suffering from a disease, and had a larger need for diagnosis and treatment by doctors. There was also a trend for non-consulting parents to feel more capable of coping with their child's stomachaches. Pearson correlations revealed that the longer the child suffered, the more likely the parents were to worry about pain, feared a disease, felt their child had a high complaint threshold, and felt it was less likely the child faked pain. In addition, increasing child age was associated with more pain worries, feeling better able to cope, and thinking that the child does not complain easily or fakes the pain, and more influence of exacerbating factors (such as stress) was acknowledged.

The questionnaire appeared to work well to identify parental worries and concerns about abdominal pain in the first study. However, concerns that there could have been something unusual about the parents who participated through the web site, we then carried out a new study in a different group of families who were identified by surveying fourth grade students in three school districts in North Carolina. One-hundred and seventeen mothers completed the PWRQ. Internal consistency of the whole scale (Cronbach's  $\alpha = 0.95$ ) as well as the subscales was moderate to good ( $.60 < \alpha < .94$ ). Parents were divided into three groups:

- 1) Healthy controls included 36 families in which the child did not suffer from stomachaches in the past three months,
  - 2) RAP non-consulters consisted of 40 families with children suffering from stomachaches at least three days out of the past three months, but who did not consult a doctor for the stomachaches, and
  - 3) RAP consulters were 41 families where the child suffered from stomachaches at least threedays out of the past three months and consulted a doctor for the stomachaches.
- Significant differences between groups were found on most subscales.

In comparison to the healthy control group, parents of RAP children worried more about pain, felt their child complained less easily or was less likely to fake pain, felt less able to cope with stomachaches, and cited more exacerbating factors like stress. Consulters differed from non-consulters on pain worries, which were higher in the consulters.

Furthermore, healthy controls and RAP non-consulters felt less need for diagnosis, care, and relief than RAP consulters. Interestingly, the three groups did not differ on the fear of disease subscale. We concluded that the PWRQ has very good internal consistency in both studies and can validly distinguish between consulting and non-consulting families. The previously reported subscales were developed based on our theory of how the questions should be grouped together, rather than

examining how people actually answer the questions. Therefore, the scales may not necessarily include the items that best discriminate consulters from nonconsulters.

We performed further statistical analyses (stepwise discriminant analyses) on the combined data of study 2 and 3 to see which individual items separated the consulters from the non-consulters. Table 1 shows the four items that contributed significantly to the discrimination of consulters from non-consulters. Based on these four items, 76.6% of the non-consulting groups could be correctly classified and 77.5% of the consulting group.

**TABLE 1**

**ITEMS THAT DISTINGUISH CONSULTERS FROM NON-CONSULTERS**

- 1) I am frustrated with my child's doctor for failing to tell me what is wrong with my child
- 2) I would like doctors to suggest a treatment
- 3) I worry about my child missing things because of his/her stomachaches
- 4) It is okay to dismiss my child's stomachaches

To confirm these results, we performed similar analyses predicting school absences for stomachaches. School absence data was only collected in the last study. Healthy controls were not included in this analysis. In the RAP groups, 56% reported that their child missed school one day or less in the last three months, and 35% reported that their child missed more than one day because of stomachaches. In a stepwise discriminant analysis, school absence was predicted by 9 items which correctly classified 84.2% of the children missing one day or less of school and 76.5% of those who missed more than one day of school.

**TABLE 2**

**ITEMS DISTINGUISHING CHILDREN WITH >1 DAY OF SCHOOL ABSENCE IN LAST 3 MONTHS**

- 1) My child complains about stomachaches easily
- 2) I am afraid to ignore things that should be checked by a doctor
- 3) I worry that my child will have stomachaches for the rest of his/her life
- 4) I worry what to do when my child has stomachaches
- 5) I worry that my doctor does not understand my child's stomachaches
- 6) I believe my child exaggerates or fakes stomachaches
- 7) I feel frustrated with my child's doctor for suggesting that my child is faking the stomachaches
- 8) I believe a lack of exercise might be related to my child's stomachaches
- 9) I worry about my child's stomachaches affecting his/her school performances.

These data indicate that it might be possible to shorten the questionnaire considerably. The current studies are limited by size, which means that we could obtain somewhat different results if we studied larger numbers of families or families recruited in a different way.



Therefore, we need to confirm our findings in a larger sample before deciding to shorten the 51-items questionnaire to a smaller scale that can be reliably used as a screening tool.

Ultimately, our goal is to understand the fears and worries of parents that are associated with consulting a doctor for RAP and with keeping the child out of school. This will give us important information on the types of cognitions that we need to address in order to help parents cope more effectively with their child's abdominal pain as well as to prevent lifelong disabling stomach aches in children.

We would like to thank all the parents that have taken the time to participate in our studies and give us very valuable information on their thoughts and feelings about RAP. Readers interested in participating and completing the questionnaire should go to our Center's website ([www.med.unc.edu/ibs](http://www.med.unc.edu/ibs)).

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