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# BMJ Open

## Children with chronic abdominal pain and their families. A three-year follow-up interview study

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3 **Children with chronic abdominal pain and their families. A three-year follow-**  
4 **up interview study**  
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## ABSTRACT

**Objective** Functional abdominal pain is a common symptom in children and adolescents. Three years ago, we investigated the experiences among parents whose children had chronic abdominal pain but no somatic diagnosis. The aim of the present follow-up study was to explore those families' current situations.

**Design** Interviews with open questions about the families' current pain situations were carried out by the first author. Interviews were audio recorded and transcribed, and subsequently analysed using descriptive content analysis.

**Setting** Urban and rural areas in two municipalities in Southern Norway.

**Participants** Parents of children with abdominal pain, who had been referred to a local hospital by their general practitioner and had been discharged without a somatic diagnosis. Fifteen parents of 14 children aged 8-17 years who had also been interviewed in 2016.

**Results** Nine of the children had recovered from their abdominal pain. During the pain period, the parents reported frustration with not having a diagnosis or a specific treatment for their child's abdominal pain. The siblings in some families received less attention and were afraid that something serious might happen to their sister or brother. The parents wished that their child's school cared more about the child when they had weeks of absence. All parents maintained that their child's pain was physical, though they thought that school problems might have influenced the symptoms. The parents stated that they as well as their children needed guidance from professionals to understand the complex pain situation.

**Conclusions** For children with chronic abdominal pain, excluding a somatic aetiology is insufficient. Families need support and pain management strategies to help deal with their situation.

### Strengths and limitations of this study

- All parents who had been interviewed three years ago agreed to be interviewed again.
- The same researcher carried out the all interviews in 2016 as well as now.
- The sample size is small, and only parents well integrated into the society were approached.

### INTRODUCTION

Functional gastrointestinal disorders (FGIDs) is a common diagnosis among children and adolescents with gastrointestinal tract symptoms who present to primary care physicians or gastroenterologists. The Rome criteria have become the standard for defining FGIDs, which are characterized by chronic or recurrent digestive symptoms without an underlying somatic disease or biochemical abnormality<sup>1</sup>. The diagnosis is based exclusively on symptoms reported by the children and the parents and the condition has no biological markers of the condition<sup>1</sup>.

In 1958, the British paediatrician John Apley published his pioneering research into children with abdominal pain, which was then called recurrent abdominal pain (RAP), this has now been replaced by FGIDs. Apley found that 11% of British schoolchildren had FGIDs and stated. "It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment"<sup>2</sup>. He was the first to establish criteria to define FGIDs as a distinct syndrome<sup>3</sup>.

Complaints of chronic abdominal pain occur in 10-19% of children, with prevalence highest in children aged four to six years and in early adolescents<sup>4</sup>.

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3 The prevalence rates of chronic abdominal pain among school-age children in  
4 the United States and Europe range from 0.3-19%<sup>5</sup>. In almost 90% of these  
5 children, no explanatory organic cause can be identified<sup>6</sup>. There are no  
6 significant differences in FGIDs related to sex, race or ethnic groups, except in  
7 functional constipation. There is overlap between parental and child FGIDs  
8 symptoms. Children with FGIDs report a lower quality of life compared to  
9 healthy children<sup>7</sup>.

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11  
12 The child's, or adolescent's and the family's life quality are negatively  
13 impacted by chronic abdominal pain. Families of children with chronic pain  
14 generally have poorer family functioning than do healthy populations. Pain-  
15 related disability is more consistently linked to family function than to pain  
16 intensity<sup>8</sup>. Research has demonstrated that parents of children with chronic  
17 pain also experience negative mental and social outcomes<sup>9</sup>. Understanding the  
18 cause of the pain seems to be important for recovery, and parents tend to be  
19 open to psychosocial interventions for their child's pain, such as stress  
20 reduction or relaxation exercises and want to discuss both physical and  
21 psychological etiological factors and treatment opinions<sup>10</sup>. Difficulties within  
22 the family may increase the child's pain, which may, in turn, negatively affect  
23 the parents and family life<sup>11</sup>. Young people with chronic pain and their parents  
24 often experience uncertainty about the diagnosis, which may be linked to their  
25 acceptance of it and response to treatment<sup>12</sup>. Parents frequently state that  
26 they feel helpless when faced with their child's suffering. These fears and  
27 worries may explain why parents reinforce illness behaviours by showing  
28 empathy for an apparently sick child<sup>13</sup>.

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31 In a study published in 2016, we carried out interviews with the parents  
32 of 14 children with chronic abdominal pain who had been discharged from the  
33 hospital without a somatic explanation<sup>14</sup>. Three years after the first interviews,  
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3 we wanted to learn how these the children and their families were progressing,  
4 by again interviewing the parents. To our knowledge, a follow-up study such as  
5 this has not been previously conducted. Thus, our aim was to investigate the  
6 course of the child's abdominal pain, what may have helped, how the family's  
7 situation had been influenced, and whether they had any unmet needs.  
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## 20 **METHODS**

### 21 *Participants*

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24 In 2016 the first author carried out an interview study with 15 parents of 14  
25 children with chronic abdominal pain<sup>14</sup>. At that time, the children were 5-15  
26 years old and had been referred to a hospital in a medium-sized Norwegian city  
27 that serves 40 000 inhabitants. The child's general practitioner (GP) had not  
28 found an explanation for the abdominal pain, and subsequent hospital  
29 investigations had not revealed any specific pathology. The parents had agreed  
30 to be interviewed again in three years. In 2019, the first author contacted the  
31 parents and arranged an interview meeting. All parents accepted the invitation.  
32 The only exclusions criterion was an inability to communicate in the  
33 Norwegian. As in 2016 a qualitative design with individual interviewer was used  
34 and a semi-structural interview guide was developed by the research team.  
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### 51 *Interviews*

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53 The parents were interviewed by the first author, a female GP who is also a  
54 child and adolescent psychiatrist. The interviews took place in locations that  
55 suited the parents: usually at the interviewer's office or at the parents'  
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3 workplaces. Four interviews were conducted by phone because the parents  
4 had moved or were on vacation. Each interview lasted 30-60 minutes. An  
5 interview guide was used (Figure 1).  
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### 10 11 12 *Data analysis*

13 The first author audio recorded and transcribed the interviews. Qualitative  
14 content analysis was conducted based on work by Graneheim and Lundman <sup>15</sup>.  
15 Both authors read the transcripts individually and worked together on their  
16 interpretation to achieve a common understanding and to reinforce the level of  
17 trust and credibility <sup>15</sup>.  
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20 The transcripts were read several times. The text was sorted into meaning  
21 units, shortened and coded. These codes were then sorted into categories and  
22 sub-categories. From the categories, three main themes emerged.  
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### 26 27 28 *Patient and public involvement*

29 No patients involved.  
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## 34 35 36 **RESULTS**

### 37 38 39 *Participant and child information*

40 In total, 15 parents of 14 children were interviewed - nine mothers, four  
41 fathers, and one couple. Ten of the parents were ethnic Norwegians. Four were  
42 of foreign origin but had lived in Norway for several years and spoke  
43 Norwegian fluently. All but two parents currently cohabitated with their child's  
44 other parent.  
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47 In 2016, the interviewed children, seven boys and seven girls, were 5-15  
48 years old; during the present interviews they were 8-18 years old. Thirteen  
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children had siblings; nine had one sibling, two had two siblings, and two had three siblings.

### *Current status of the children's abdominal pain*

In the three years since the original interview, the abdominal pain had improved in nine of the children, and persevered in three of them. In two of the children, the situation was unclear. The boys and the girls who had recovered ranged in age from 10.5-17 years and 8.8-15 years, respectively (Table 1).

Table 1: Current status of the children's abdominal pain

	Total number	Girls	Boys
Recovered	9	4	5
Still symptoms	3	1	2
Unsure situation	2	2	0

We identified three main themes:

- 1) How has the child's abdominal pain affected the family during the last three years?
- 2) What contributed to reducing the child's pain and what were the consequences of improvement?
- 3) What were the families' present needs?

*Theme 1: How has the child's abdominal pain affected the family during the last three years?*

#### *Increased burden on parents*

Nearly all the parents reported that the child's pain had affected their family. Half of the children (three boys and four girls) had been absent from school, six

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3 of them had missed several weeks. The parents had to stay home from work or  
4 arrange for a caregiver on these days. *“It is a mental strain, especially the*  
5 *absence from work” (Interview No 8).*

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10 *“We tried to avoid being absent from work. The grandparents stayed with her.*  
11 *In the end I had to get a sick leave because she was at home for more than two*  
12 *months” (Interview No 14).*

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16 Some parents had to stay with their child all day and night. *“She was sick*  
17 *at night too. We became like zombies. We slept some hours each in her room.*  
18 *We ate in bed together with her” (Interview No 14).*

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22 *“It has affected the family dynamics. We used to eat meals together, but when*  
23 *he has pain, he wants to delay eating” (Interview No 1).*

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27 *“Every evening, her mother talks with her for more than one hour trying to calm*  
28 *her down and get her to sleep” (Interview No 11).*

### 32 33 *Effect on siblings*

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35 Siblings' reaction varied widely from not noticing the symptoms at all to being  
36 significantly affected. *“His big brother thinks he is a drama queen, that he*  
37 *exaggerates the symptoms” (Interview No 8).*

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42 In several of the families, younger siblings expressed difficulties with  
43 having an older brother or sister who experienced abdominal pain. *“His little*  
44 *brother gets a little overlooked because his sister takes such a great pass. I*  
45 *myself as mother feel pity for him” (Interview No 4).*

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50 *“He talked about his dark thoughts at home. That was tough for his little*  
51 *brother to hear. He got sad and his teacher noticed that. The atmosphere in the*  
52 *house was the worst” (Interview No 10).*

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57 *“Her little brother was very worried. He wondered if she was going to die and*  
58 *did not want to be home alone with her” (Interview No 14).*

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5 *Parents' worries about their child*

6 Some parents feared that their worries could negatively affect the child. Not  
7  
8 knowing the diagnosis and fear of serious illness influenced their everyday  
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10 lives. *"My frustration spreads to him and so he reads me and I read him"*  
11  
12 *(Interview No 2).*

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17 *Theme 2. What contributed to reducing the child's pain and what were the*  
18 *consequences of improvement?*

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21 Nine of the 14 children (five boys and four girls) had recovered by the time of  
22  
23 the follow-up interview. For six of these, the parents did not know the reason  
24  
25 for the child's recovery. Three of the children had been helped by treatments  
26  
27 for constipation and reflux symptoms. One parent explained: *"The pain*  
28  
29 *disappeared, the child just grew out of it"* *(Interview No 7).*

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32 One parent wondered what the child meant by "stomach pain" because  
33  
34 she did not appear to be in pain. *"She cannot define it more clearly herself. Is*  
35  
36 *this real pain or is it more a feeling of "air in the guts"?* *(Interview No 13).*

37  
38 Recovery from abdominal pain also influenced the families. *"Her mood is*  
39  
40 *much better now, so that makes it easier for her siblings and I can lower my*  
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42 *shoulders"* *(Interview No 1).*

43  
44 *The whole situation is better for all now that the diagnosis is known"* *(Interview*  
45  
46 *No 6).*

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49 The children did not want their parents to worry, in turn the parents  
50  
51 wondered whether their children answered questions accurately or hid their  
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53 symptoms. They also wondered how this long pain period would affect the  
54  
55 child's development. *"This stomach pain has lasted several years. What will this*  
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57 *do to him as a person? How will he be as an adult"?* *(Interview No 1).*  
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3 All the parents thought, as they did in 2016, that the abdominal pain was  
4 a physical condition. However, some also thought that there could be  
5 psychological factors (such as school problems, problems with friends etc.) that  
6 affected the pain. Four of the children had talked to a child and adolescent  
7 psychologist, another one parents had asked for that type of appointment, but  
8 their request was not fulfilled. Two children had contact with a family member  
9 with psychological expertise. Two parents reported that their child did not  
10 need to talk to a psychologist.  
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### 22 *Theme 3: What were the families' present needs?*

#### 23 *Desire for a diagnosis*

24 Some of the parents emphasized that getting a diagnosis had made the child  
25 better.  
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30 *"He was terrified, had stomach pain all the time and did not understand why. It*  
31 *helped him a lot to get the diagnosis and know that we could do something*  
32 *about it" (Interview No 10).*  
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37 A diagnosis was important to the parents. The discussion about when to  
38 stop pursuing further examinations in pursuit of a diagnosis was difficult. *"We*  
39 *are so desperate about the pain situation. I am fully aware of the academic*  
40 *foundation, that it is expensive and takes resources, but as a parent it would*  
41 *have calmed me down" (Interview No 1).*  
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48 Some of the parents reported frustration with the follow-up from the  
49 hospital. *"We want a more specific feedback and more information from the*  
50 *doctor. I have to be a nutritionist myself to help my child" (Interview No 13).*  
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54 *"I want more co-operation between patient/parents and hospital, it would*  
55 *have made the treatment more effective. it is important to look at the whole*  
56 *story, all factors together". (Interview No 10).*  
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### *Worries about the school situation*

More than half of the parents were concerned about their child's school situation and that the abdominal pain was influenced by problems there. Some of the parents reported that when the school situation got better, the child's abdominal pain also recovered. *"She has started secondary school, started in a new class and is much better physically as well as psychologically"* (Interview No 11).

The parents argued that children and adolescents were under a great deal of stress and that school contributed to this. Some of the parents worried that the school was not taking the situation seriously. *"The child had been absent from school from a few days to several weeks and they had not received a special program from school"* (Interview No 2).

*"There is little communication with the school. We had hoped that the school had something to contribute. They knew about the problems, but did not take us seriously"* (Interview No 11).

## **DISCUSSION**

Fifteen parents of 14 children with FGIDs, who had been discharged from hospital without an identified somatic cause were interviewed in 2016 and again for the present study in 2019. During the intervening years, nine children had recovered from their abdominal pain. For six of these, no reason for their recovery had been identified. During the pain periods the parents reported frustration with not having a somatic diagnosis for their child. They expressed a desire for closer contact, more information, and a specific pain treatment. The school situation was mentioned by the parents as a factor that influenced their

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3 child's symptoms. The parents also reported that the whole family was affected  
4 by the child's abdominal pain.  
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7         Some of the children had days, or even weeks, when they were absent  
8 from school. On these days, the parents or grandparents stayed home from  
9 work to look after the child. Lowth reported that parents should be advised to  
10 reduce concerned responses to their child's pain, focusing on distraction  
11 instead. Children should attend school irrespective of pain. This can be initially  
12 difficult, however, progress is often rapid <sup>16</sup>. Making the child attend school  
13 was often very hard for parents in the current study. They felt that doing so  
14 was inhumane, which led to family discussions. Parents need much support to  
15 be consistent in following-up with their child. Walker et al wrote "The parent's  
16 role and mindset must change. Until now, the parent's job was to protect the  
17 child from possible harm while searching for a cause of the pain. Emphasize  
18 that the parent's job now is to be a "coach", to encourage and support the  
19 child's return to normal activities. Even children with organic disease — such as  
20 diabetes or cystic fibrosis attend school" <sup>17</sup>.  
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37         The pain topic could also tie the family together, as a problem they have  
38 in common and on which they must cooperate. Sjøgård wrote: "Parents with a  
39 chronically ill child live in a constant battle. A never-ending battle between  
40 something good and bad. To live with a chronically ill child is challenging for the  
41 whole family" <sup>18</sup>. Siblings of children with FGIDs have been reported to have  
42 significantly higher mean levels of emotional and/or behavioural symptoms  
43 compared with the siblings of comparable, healthy children <sup>19</sup>. In families with  
44 more than one child the parents' tasks seem complex, needing to care for both  
45 the child with pain and their siblings.  
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56         Some parents worried about the impact of long-term pain on their child's  
57 development. Reid et al wrote: "This raises questions about the long-term  
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3 impact of persistent chronic pain on children's development and success  
4 stepping forward into adulthood. This is an important topic for future  
5 research."<sup>20</sup> Michael Balint wrote about the concept of "the child as the  
6 presenting symptom"<sup>21</sup>. When a child was repeatedly taken to see a GP, it was  
7 often found that the parent also needed therapy, usually of an emotional,  
8 psychological nature. These families often seem vulnerable to being  
9 misunderstood and misinterpreted. Consequently, their doctors should be both  
10 agile and clear with treatment recommendations.<sup>21</sup> Some of the parents in our  
11 study raised the question of whether their worries about their child's  
12 symptoms might impact the child and maintain their pain. Palermo stated "The  
13 parent's behavior is conceptualized as operant factors that serve to either  
14 increase or decrease adaptive child behavior"<sup>22</sup>. Lask et al. conclude that it is  
15 important to both exclude organic causes and to identify positive indications of  
16 emotional problems. Careful explanation and patient discussion with the  
17 parents are both essential<sup>23</sup>. These authors also use the expression "grew out  
18 of it"<sup>23</sup>. The parents in our study had similar conclusions regarding six of the 14  
19 children.

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22 In our study all the parents believed their child's abdominal pain had  
23 physiological causes, although some thought psychological aspects could  
24 impact the symptoms. Crushell et al. found that only one in 14 parents of  
25 children with ongoing pain believed that there was a psychological cause for  
26 their child's pain<sup>24</sup>. Psychological interventions for managing paediatric chronic  
27 pain have involved the parents in treatment using this approach, (i. e. teaching  
28 the parents techniques to increase adaptive child behaviour such as rewarding  
29 the child's school attendance)<sup>23</sup>. Parents' problem-solving methods-overall,  
30 not just regarding health problems, usually affect their children. The adults in a  
31 family are, in most cases, the child's role models. Palermo reported that  
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3 parents' emotions, behaviours, and health play a role in children's pain  
4 experiences.<sup>25</sup>  
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7 Reid et al. stated that parents' responses demonstrate a clear desire for  
8 information about the causes of their child's pain, treatment options available  
9 at the pain clinic, effective strategies to enhance their child's ability to cope  
10 with pain, and the effects of pain on both the child's body and mood<sup>20</sup>. The  
11 parents in our study reported in both interviews (i.e. in 2016 and again in 2019)  
12 that it was frustrating not having a diagnosis. Treatment of the abdominal pain  
13 became difficult when the diagnosis was uncertain. The parents felt that they  
14 had to be "a nutritionist themselves" and had to give their child food advice.  
15 They worried that the child could have a serious diagnosis. Having had  
16 somebody to talk to about the pain or being provided with an explanation from  
17 the doctor would have made the situation better. In addition, an appointment  
18 with a psychologist would have made the situation easier. Although two  
19 parents stated that their child did not need a psychologist, there was a positive  
20 attitude among the other parents about having a psychologist on the  
21 treatment team. Lowth stated "The most important therapeutic step is to  
22 explain the diagnosis, explain strategies to cope with stress and provide  
23 reassurance that there is no serious underlying disease"<sup>16</sup>.  
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44 Many of the parents were concerned about school. They wanted close  
45 co-operation with their child's school and expressed that this was a  
46 prerequisite for successful treatment. Returning to school is an important part  
47 of helping a child with functional pain to improve. The goal of treatment is a  
48 return to normal activities, rather than removing pain.  
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### 56 *Strengths and limitations*

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3 The first author and interviewer is a GP and a child and adolescent psychiatrist.  
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5 When conducting all the interviews, in both 2016 and 2019, she presented  
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7 herself as a scientist. We expect that this improved both the interview quality  
8  
9 and interpretation. The interview participants were mainly ethnic Norwegians,  
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11 other ethnic groups might have responded differently.  
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## 16 **Conclusion**

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18 Interviews with the parents of children with FGIDs that were conducted in 2016  
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20 were repeated in 2019 for this follow-up study. Nine of the 14 children and  
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22 adolescents had recovered during this period. For six, the reason for recovery  
23  
24 was unknown; the parents explained that they “grew out of it”. These parents’  
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26 desire for a diagnosis and more guidance from their child’s doctor remained  
27  
28 important. Closer co-operation with the school was also desired, as some of  
29  
30 the children had weeks of absence from school and were partly isolated in  
31  
32 terms of both school subjects and social contact. Physicians with an interest in  
33  
34 FGIDs and who can provide psychoeducation for these families are needed.  
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## 40 **Author contribution**

41  
42 Both authors planned the study. MB applied for ethics approval. AB carried out  
43  
44 the interviews and transcribed the text, and both authors participated in the  
45  
46 analyses. AB drafted the article, and MB revised it critically.  
47  
48  
49

## 50 **Ethics approval**

51  
52 The Regional Committees for Medical and Health Research Ethics approved the  
53  
54 study (reference no. 2019/646). The study has followed the operational  
55  
56 principles of the Declaration of Helsinki and adhered to the Belmont Report  
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3 principles (i.e.respect for persons; beneficence; and justice) in obtaining valid  
4 informed consent from parents.  
5

6  
7 The parents gave written consent to participate. Even when only one of the  
8 parents was interviewed both parents signed the declaration of consent. The  
9 children and adolescents were informed about the study through an  
10 information letter, and children 16 years or older provided a written consent  
11 stating that their parent(-s) could participate.  
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### 20 **Disclosure statement**

21  
22 The authors report no conflicts of interests.  
23  
24  
25

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27  
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29  
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Table 1

## Current status of the children's abdominal pain

	Total number	Girls	Boys
Recovered	9	4	5
Still symptoms	3	1	2
Unsure situation	2	2	0

For peer review only

Figure 1 Interview guide

1. Concerning the stomach pain – how is your child doing at present?
2. Concerning the stomach pain – how has the situation been during the last 3 years?  
For the child? For the family?
3. How has the child's pain affected the family? Parents? Siblings?
4. How has improvement or worsening of the pain affected the family?
5. Has the child been followed up by a GP or by the hospital during the last 3 years?
6. Has the child seen any other health personnel?
7. What do you think has contributed to the child's improvement/worsening?
8. Is there anything more I should have asked?
9. How did you experience this interview?

# BMJ Open

## Understanding parents' experiences of disease course and influencing factors: A three-year follow-up qualitative study among parents of children with functional abdominal pain

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Manuscript ID	bmjopen-2020-037288.R1
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Manuscripts





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3 **Understanding parents' experiences of disease course and influencing factors:**  
4 **A three-year follow-up qualitative study among parents of children with**  
5 **functional abdominal pain**  
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12 Anne Brodwall<sup>1,2</sup>, Mette Brekke<sup>3</sup>  
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## ABSTRACT

**Objective** Functional abdominal pain is a common symptom in children and adolescents. Three years ago, we investigated the experiences among parents whose children had chronic abdominal pain but no somatic diagnosis. The aim of the present follow-up study was to explore those families' current situations.

**Design** Interviews with open questions about the families' current pain situations were carried out by the first author. Interviews were audio recorded and transcribed, and subsequently analysed using descriptive content analysis.

**Setting** Urban and rural areas in two municipalities in Southern Norway.

**Participants** Parents of children with abdominal pain, who had been referred to a local hospital by their general practitioner and had been discharged without a somatic diagnosis. Fifteen parents of 14 children aged 8-17 years who had also been interviewed in 2016.

**Results** Nine of the children had recovered from their abdominal pain. During the pain period, the parents reported frustration with not having a diagnosis nor a specific treatment for their child's abdominal pain. The siblings in some families received less attention and were afraid that something serious might happen to their sister or brother. The parents wished that their child's school cared more about the child when they had weeks of absence. All parents maintained that their child's pain was physical, though they thought that psychological aspects might have influenced the symptoms. The parents stated that they as well as their children needed guidance from professionals to understand the complex pain situation.

**Conclusions** For children with chronic abdominal pain, excluding a somatic aetiology is insufficient. Families need support and pain management strategies to help deal with their situation.

## Strengths and limitations of this study

- The main strength of the present study is that the complete cohort of parents who had been interviewed three years ago agreed to be interviewed again.
- A strength is also that the same researcher carried out all interviews on both occasions.
- The use of semi-structured interviews enabled detailed information about the parents' experiences over the three years.
- The sample size is small, and with one exception, only one of the parents in each family was interviewed.
- Only parents well integrated into the society were approached.

## INTRODUCTION

Functional gastrointestinal disorders (FGIDs) is a common diagnosis among children and adolescents with gastrointestinal tract symptoms who present to primary care physicians or gastroenterologists. The Rome criteria have become the standard for defining FGIDs, which are characterized by chronic or recurrent digestive symptoms without an underlying somatic disease or biochemical abnormality<sup>1</sup>. The diagnosis is based exclusively on symptoms reported by the children and the parents and the condition has no biological markers<sup>1</sup>.

In 1958, the British paediatrician John Apley published his pioneering research into children with abdominal pain, which was then called recurrent abdominal pain (RAP), this has now been replaced by FGIDs. Apley found that 11% of British schoolchildren had FGIDs and stated: "It is a fallacy that a physical

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3 symptom always has a physical cause and needs a physical treatment”<sup>2</sup>. He  
4 was the first to establish criteria to define FGIDs as a distinct syndrome<sup>3</sup>.

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7       Complaints of chronic abdominal pain occur in 10-19% of children, with  
8 prevalence highest in children aged four to six years and in early adolescence<sup>4</sup>.  
9  
10 The prevalence rates of chronic abdominal pain among school-age children in  
11 the United States and Europe range from 0.3-19%<sup>5</sup>. In almost 90% of these  
12 children, no explanatory organic cause can be identified<sup>6</sup>. There are no  
13 significant differences in FGIDs related to sex, race or ethnic groups, except in  
14 functional constipation, which is significantly more prevalent in males  
15 compared to females<sup>7</sup>. There is overlap between parental and child FGIDs  
16 symptoms. Children with FGIDs report a lower quality of life compared to  
17 healthy children<sup>7</sup>.

18  
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20       The child’s or adolescent’s and their family’s life quality are negatively  
21 impacted by chronic abdominal pain. Families of children with chronic pain  
22 generally have poorer family functioning than do healthy populations. Pain-  
23 related disability is more consistently linked to family function than to pain  
24 intensity<sup>8</sup>. Research has demonstrated that parents of children with chronic  
25 pain also experience negative mental and social outcomes<sup>9</sup>. Understanding the  
26 cause of the pain seems to be important for recovery, and parents tend to be  
27 open to psychosocial interventions for their child’s pain, such as stress  
28 reduction or relaxation exercises and want to discuss both physical and  
29 psychological etiological factors and treatment opinions<sup>10</sup>. Difficulties within  
30 the family may increase the child’s pain, which may, in turn, negatively affect  
31 the parents and family life<sup>11</sup>. Young people with chronic pain and their parents  
32 often experience uncertainty about the diagnosis, which may be linked to their  
33 acceptance of it and response to treatment<sup>12</sup>. Parents frequently state that  
34 they feel helpless when faced with their child’s suffering. These fears and  
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worries may explain why parents reinforce illness behaviours by showing empathy for an apparently sick child <sup>13</sup>.

In a study published in 2018, we carried out interviews with parents of 14 children with chronic abdominal pain who had been discharged from the hospital without a somatic explanation <sup>14</sup>. The study concluded that functional pain in children and adolescents is challenging for the patient and the family and that they often need medical support for a long period. Three years after the first interviews, we wanted to learn how these the children and their families were progressing, by again interviewing the parents. By following these families over some years, we could gain valuable information about the children's symptoms and treatment. To our knowledge, a follow-up qualitative study such as this has previously not been conducted in this patient group. Thus, our aim was to investigate the course of the child's abdominal pain, what may have helped, how the family's situation had been influenced, and whether they had any unmet needs.

## **METHODS**

### *Participants*

In 2016, the first author carried out an interview study with 15 parents of 14 children with chronic abdominal pain <sup>14</sup>. She deliberately aimed at a broad age span (from 5 to 15 years), and the children included were between 6 and 13.5 years old. All had been referred to a hospital in a medium-sized Norwegian city that serves 40 000 inhabitants. The child's general practitioner (GP) had not found an explanation for the abdominal pain, and subsequent hospital investigations had not revealed any specific pathology. The only exclusions criterion was an inability to communicate in the Norwegian language. Recruitment was carried out consecutively face to face among eligible families

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2  
3 by a nurse at the hospital. After 14 interviews, data saturation had been  
4 reached and recruitment stopped. Details about the original recruitment  
5 process are given in our previous article <sup>14</sup>. The parents also agreed to be  
6 invited to an interview again in three years. In 2019, the first author contacted  
7 the parents by telephone and arranged an interview meeting. All parents  
8 accepted the invitation. As in 2016, a qualitative design with individual  
9 interviews was used.  
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### 21 *Interviews*

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23 The parents were interviewed by the first author, a female GP who is also a  
24 child and adolescent psychiatrist and works at the hospital's child psychiatric  
25 department. The parents knew that the interviewer was a physician; in the  
26 interview setting, however, she presented herself as a researcher with a special  
27 interest in FGIDs, but with no therapeutic responsibility. The interviewer was  
28 empathetic, though neutral, and encouraged the parents to speak freely. The  
29 interviews took place in locations that suited the parents: usually at the  
30 interviewer's office or at the parents' workplaces, with no-one else present.  
31 Four interviews were conducted by phone because the parents had moved or  
32 were on vacation. Each interview lasted 30-60 minutes. A semi-structural  
33 interview guide was used by the author, but not provided to the participants  
34 (Figure 1). The first author audio recorded and transcribed the interviews. The  
35 transcripts were not returned to the participants for comments.  
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### 55 *Data analysis*

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57 Qualitative content analysis was conducted based on work by Graneheim and  
58 Lundman <sup>15</sup>. Both authors read the transcripts individually and worked together  
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3 on their analysis to achieve a common understanding and to reinforce the level  
4 of trust and credibility<sup>15</sup>. The transcripts were read several times. The text was  
5 sorted into meaning units, shortened and coded. These codes were then sorted  
6 into categories and sub-categories. From the categories, three main themes  
7 emerged. No software tool was used for the analyses. The authors discussed  
8 the codes, categories and themes until agreement was reached. The themes  
9 were derived from the data, not identified in advance.  
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### 20 *Patient and public involvement*

21 No patients involved.  
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## 29 **RESULTS**

### 30 *Participant and child information*

31 In total, 15 parents of 14 children were interviewed - nine mothers, four  
32 fathers, and one couple. Ten of the parents were ethnic Norwegians. Four were  
33 of foreign origin but had lived in Norway for several years and spoke  
34 Norwegian fluently. All but two parents currently cohabitated with their child's  
35 other parent. In 2016, the interviewed children, seven boys and seven girls,  
36 were 6-13.5 years old; during the present study they were 9-17 years old.  
37 Thirteen children had siblings; nine had one sibling, two had two siblings, and  
38 two had three siblings.  
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### 52 *Current status of the children's abdominal pain*

53 In the three years since the original interview, nine of the children had  
54 recovered from abdominal pain, and in three of them the pain persevered. In  
55 two of the children, the situation was unclear (Table 1). "Recovered" was  
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3 defined as no subjective complaints and return to school and other activities.  
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5 The boys and the girls who had recovered ranged in age from 10.5-17 years and  
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7 8.8-15 years, respectively. The three children who still had pain were 9, 10 and  
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9 11.5 years old.  
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15 Table 1: Current status of the children's abdominal pain

	Total number	Girls	Boys
Recovered	9	4	5
Still symptoms	3	1	2
Unsure situation	2	2	0

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26 We identified three main themes:

- 27 1. Family burden and frustration - and how school issues implied a major  
28 dilemma.
- 29 2. The consequences of improvement.
- 30 3. Desire for a diagnosis and for advice.

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39 *Theme 1: Family burden and frustration - and how school issues implies a major  
40 dilemma*

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43 Nearly all the parents reported that the child's pain had affected their family.  
44  
45 Half of the children (three boys and four girls) had been absent from school, six  
46  
47 of them had missed several weeks. The parents had to stay home from work or  
48  
49 arrange for a caregiver on these days. *"We tried to avoid being absent from  
50 work. The grandparents stayed with her. In the end I had to get a sick leave  
51 because she was at home for more than two months" (Interview No 14).*

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56 Some parents had to stay with their child all day and night. The strain  
57  
58 affected the family dynamics, and disrupted the normal daily life in the family,  
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3 like having common meals and normal sleeping patterns. *"She was sick at night*  
4 *too. We became like zombies. We slept some hours each in her room. We ate in*  
5 *bed together with her"* (Interview No 14). Some parents feared that their  
6  
7  
8 worries could negatively affect the child. Not knowing the diagnosis and fear of  
9  
10 serious illness influenced their everyday lives. *"My frustration spreads to him*  
11 *and so he reads me and I read him"* (Interview No 2).  
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### 18 *Effect on siblings*

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20 Siblings' reaction varied widely from not noticing the symptoms at all to being  
21 significantly affected. *"His big brother thinks he is a drama queen, that he*  
22 *exaggerates the symptoms"* (Interview No 8). In several of the families, younger  
23  
24 siblings expressed difficulties with having an older brother or sister who  
25  
26 experienced abdominal pain. The parents had less time to take care of the  
27  
28 siblings. *"His little brother gets a little overlooked because his sister takes such*  
29 *a great pass. I myself as mother feel pity for him"* (Interview No 4).  
30  
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35 Some of the siblings' teachers had notices that the child was affected by the  
36 situation at home. *"He talked about his dark thoughts at home. That was tough*  
37 *for his little brother to hear. He got sad and his teacher noticed that. The*  
38 *atmosphere in the house was the worst"* (Interview No 10).  
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### 45 *The school situation – a major dilemma*

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47 More than half of the parents were concerned about their child's school  
48 situation and that the abdominal pain was influenced by problems there. Some  
49 reported that when the school situation got better, the child's abdominal pain  
50 also recovered. *"She has started secondary school, started in a new class and is*  
51 *much better physically as well as psychologically"* (Interview No 11). The  
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3 the situation seriously. *“There is little communication with the school. We had*  
4 *hoped that the school had something to contribute. They knew about the*  
5 *problems, but did not take us seriously” (Interview No 11).*

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10 Some of the parents elaborated on their dilemma by sending the child to  
11 school on days with abdominal pain. They explained that they knew school  
12 attendance was compulsory and important for social relationships and for the  
13 treatment, yet it was problematic for the parents. They expressed fear of being  
14 poor parents by forcing their child to go. *“They told us at the hospital that she*  
15 *should try to go to school again. But I told them it will not be possible for me to*  
16 *send her to school when she has pain” (Interview No.14).*

## 26 *Theme 2. The consequences of improvement*

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29 Nine of the 14 children (five boys and four girls) had recovered by the time of  
30 the follow-up interview. For six of these, the parents did not know the reason  
31 for the child’s recovery. Three of the children had been helped by treatments  
32 for constipation and reflux symptoms. One parent explained: *“The pain*  
33 *disappeared, the child just grew out of it” (Interview No 7).* One parent  
34 wondered what the child meant by “stomach pain” because she did not appear  
35 to be in pain. *“She cannot define it more clearly herself. Is this real pain or is it*  
36 *more a feeling of “air in the guts? Could the pain be an excuse or cover other*  
37 *problems for the child”?* (Interview No 13).

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48 Recovery from abdominal pain influenced the families and made the  
49 situation better for all family members. *“Her mood is much better now, so that*  
50 *makes it easier for her siblings and I can lower my shoulders” (Interview No 1).*  
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52 The children did not want their parents to worry; in turn, the parents  
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wondered whether their children answered their questions accurately or hid  
their symptoms. They also wondered how this long pain period would affect

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3 the child's development. *"This stomach pain has lasted several years. What will*  
4 *this do to him as a person? How will he be as an adult?" (Interview No 1).*  
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10 *Theme 3: Desire for a diagnosis and for advice*

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12 Some of the parents emphasized that getting a diagnosis had made the child  
13 better. *"He was terrified, had stomach pain all the time and did not understand*  
14 *why. It helped him a lot to get the diagnosis and know that we could do*  
15 *something about it" (Interview No 10).* A diagnosis was also important to the  
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parents. The discussion about when to stop pursuing further examinations to  
find a diagnosis was difficult. To stop investigations before the child had a  
diagnosis seemed not acceptable. *"We are so desperate about the pain*  
*situation. I am fully aware of the academic foundation that it is expensive and*  
*takes resources, but as a parent it would have calmed me down" (Interview No*  
*1).*

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The follow-up from the hospital was reported as frustrating by some of  
the parents *"I want more co-operation between patient/parents and hospital, it*  
*would have made the treatment more effective. it is important to look at the*  
*whole story, all factors together". (Interview No 10).* The parents reported  
having been told that "it is up to you to try" and they missed guidance over time  
by a doctor or nurse.

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All the parents thought, as they did in 2016, that the abdominal pain was  
a physical condition. However, some also thought that there could be  
psychological factors (such as school problems, problems with friends etc.) that  
affected the pain. Four of the children had talked to a child and adolescent  
psychologist, another one parents had asked for that type of appointment, but  
their request was not fulfilled. Two children sought guidance from a family

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3 member with psychological expertise. Two parents reported that their child did  
4 not need to talk to a psychologist.  
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## 10 11 **DISCUSSION**

12  
13 Fifteen parents of 14 children with FGIDs, who had been discharged from  
14 hospital without an identified somatic cause were interviewed in 2016 and  
15 again for the present study in 2019. During the intervening years, nine children  
16 had recovered from their abdominal pain. For six of these, no reason for their  
17 recovery had been identified. The parents reported frustration with not having  
18 a somatic diagnosis for their child, they missed having closer contact with a  
19 doctor and cooperation with school was poor.  
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28 The parents thought it was impossible and inhumane to force the child to  
29 school on days with pain. Previous studies have stated the importance of school  
30 also in pain periods <sup>16,17</sup>. The parents should be advised to reduce concerned  
31 responses to their child's pain, focusing on distraction instead <sup>16</sup>. The parents'  
32 role and mindset need to be changed from protecting the child from possible  
33 harm to being a coach to encourage and support the child to engage in normal  
34 activities <sup>17</sup>. The goal of treatment thus will be return to normal activities,  
35 rather than removing pain. The parents in the current study wanted a closer  
36 co-operation with school and believed that it was a prerequisite for successful  
37 treatment. However, they emphasized that this was complicated and  
38 frustrating. This makes psychoeducation and support to these families over  
39 time an important part of the treatment <sup>16</sup>. Some parents worried about the  
40 impact of long-term pain on their child's development. This topic has been  
41 discussed in others studies <sup>18</sup>. The child's possibility to a successful stepping  
42 forwards into adult life also must be an aspect of the treatment <sup>18</sup>.  
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3 In families with more than one child, the parent's tasks seem complex, as  
4 they need to care for both the child with abdominal pain and the siblings.  
5 Parents with chronically ill children have been described to live in a never-  
6 ending battle, which is challenging for the whole family <sup>19</sup>. It is known that  
7 siblings of children with FGIDs have significantly higher mean levels of  
8 emotional and/or behavioral symptoms compared with siblings of comparable,  
9 healthy children <sup>20</sup>. The siblings' involvement in our study ranged from very  
10 serious concerns to not caring.  
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20 Michael Balint wrote about the concept of "the child as the presenting  
21 symptom" <sup>21</sup>. When a child was repeatedly taken to see a GP, it was often  
22 found that the parents also needed therapy, usually of an emotional,  
23 psychological nature. These families often seem vulnerable to being  
24 misunderstood and misinterpreted. Consequently, their doctors should be both  
25 agile and clear with treatment recommendations <sup>21</sup>. Simultaneously, a study  
26 from 2018 showed that the parents were highly strained due to the demands  
27 of their role as caregivers to a child with functional abdominal pain <sup>22</sup>. The  
28 parents' behavior can be seen as operant factors that serve to either increase or  
29 decrease adaptive child behavior <sup>23</sup>. This concern was also raised by the  
30 participants in our study, as some parents raised the question of whether their  
31 worries about their child's symptoms might impact the child and maintain their  
32 pain  
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48 It is important to both exclude organic causes and to identify eventual  
49 positive indications of emotional problems <sup>24</sup>. Crushell et al. found that only  
50 one in 14 parents of children with ongoing pain believed that there was a  
51 psychological cause for their child's pain <sup>25</sup>. All our respondents believed their  
52 child's abdominal pain had physiological causes, although some thought  
53 psychological aspects could influence the symptoms. These expressions could  
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3 explain why so few of the children had spoken to a psychologist. Nevertheless,  
4 is it important to include psychological therapy such as cognitive behavior  
5 therapy in the treatment plan <sup>16</sup>. Psychological interventions for managing  
6 paediatric chronic pain have involved the parents in treatment using this  
7 approach, i. e. teaching the parents techniques to increase adaptive child  
8 behaviour such as rewarding the child's school attendance <sup>24</sup>. Parents'  
9 problem-solving methods overall, not just regarding health problems, usually  
10 affect their children. The adults in a family are, in most cases, the child's role  
11 models. Palermo reported that parents' emotions, behaviours, and health play  
12 a role in children's pain experiences <sup>26</sup>.

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14 The expression "grew out of the pain" was used by six of the 14 parents in  
15 our study. A study from 2020 also stated that most children do not have  
16 persistent symptoms throughout childhood <sup>27</sup>. Our participants seemed to be  
17 satisfied with this solution and had no further need for more detailed knowledge.  
18 The parents in our study reported in both interviews (i.e.in 2016 and again in  
19 2019) that it was frustrating not having a diagnosis. To deal with the abdominal  
20 pain became difficult when the diagnosis was uncertain. Having had somebody  
21 to talk to about the pain or being provided with an explanation from the doctor  
22 would have made the situation better. Several studies reveal a clear desire by  
23 parents for information about the causes of their child's pain, treatment  
24 options available, and for effective strategies to enhance their child's ability to  
25 cope with pain <sup>16,20,28</sup>..

### 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 *Strengths and limitations*

52 The first author and interviewer is a GP and a child and adolescent psychiatrist.  
53 When conducting the interviews, she presented herself as a researcher, to  
54 emphasize that she had no therapeutic responsibilities in this setting and that  
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3 the parents could speak freely. We expect that this improved both the  
4 interview quality and interpretation. The interview participants were mainly  
5 ethnic Norwegians, other ethnic groups might have responded differently.  
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## 10 11 **Conclusion**

12 A child having functional pain is challenging for the child as well as the parents  
13 and siblings. The goal of the treatment is helping the child and the family to  
14 return to normal function, like attending school and other activities. This  
15 undermines the importance of psychoeducation about the symptoms and pain  
16 treatment strategies. Cognitive behaviour therapy or other psychological  
17 interventions may help the families, and follow-up over time by a trusted  
18 physician is essential.  
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## 30 31 **Author contribution**

32 Both authors planned the study. MB applied for ethics approval. AB carried out  
33 the interviews and transcribed the text, and both authors participated in the  
34 analyses. AB drafted the article, and MB revised it critically.  
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## 41 42 **Ethics approval**

43 The Regional Committees for Medical and Health Research Ethics approved the  
44 study (reference no. 2019/646). The study has followed the operational  
45 principles of the Declaration of Helsinki and adhered to the Belmont Report  
46 principles (i.e. respect for persons; beneficence; and justice) in obtaining valid  
47 informed consent from parents.  
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54 The parents gave written consent to participate. Even when only one of the  
55 parents was interviewed both parents signed the declaration of consent. The  
56 children and adolescents were informed about the study through an  
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3 information letter, and children 16 years or older provided a written consent  
4 stating that their parent(-s) could participate.  
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10 **Disclosure statement**

11 The authors report no conflicts of interests.  
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17 We are grateful to all parents sharing their experiences with us.  
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<https://www.uptodate.com/contents/functional-abdominal-pain-in->

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For peer review only

## Figure 1 Interview guide

1. Concerning the stomach pain – how is your child doing at present?
2. Concerning the stomach pain – how has the situation been during the last 3 years?  
For the child? For the family?
3. How has the child's pain affected the family? Parents? Siblings?
4. How has improvement or worsening of the pain affected the family?
5. Has the child been followed up by a GP or by the hospital during the last 3 years?
6. Has the child seen any other health personnel?
7. What do you think has contributed to the child's improvement/worsening?
8. Is there anything more I should have asked?
9. How did you experience this interview?

## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

# BMJ Open

## Understanding parents' experiences of disease course and influencing factors: A three-year follow-up qualitative study among parents of children with functional abdominal pain

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-037288.R2
Article Type:	Original research
Date Submitted by the Author:	28-Jul-2020
Complete List of Authors:	Brekke, Mette; University of Oslo Department of Health and Society Brodwall, Anne; University of Oslo Department of Health and Society
<b>Primary Subject Heading</b>:	Paediatrics
Secondary Subject Heading:	General practice / Family practice, Gastroenterology and hepatology
Keywords:	QUALITATIVE RESEARCH, PAIN MANAGEMENT, Paediatric gastroenterology < PAEDIATRICS

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3 **Understanding parents' experiences of disease course and influencing factors:**  
4 **A three-year follow-up qualitative study among parents of children with**  
5 **functional abdominal pain**  
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12 Anne Brodwall<sup>1</sup>, Mette Brekke<sup>1</sup>  
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15 **Running head:** Parents' experience of their child in chronic pain  
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18 **Article category:** Research article  
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21 **Word count:** Abstract: 267 words Article: 3 416 words  
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45 **Key words:** Paediatrics, General Practice, Gastroenterology, Pain  
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50 **ABSTRACT**  
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52 **Objective** Functional abdominal pain is a common symptom in children and  
53 adolescents. Three years ago, we investigated the experiences among parents  
54 whose children had chronic abdominal pain but no somatic diagnosis. The aim  
55 of the present follow-up study was to explore those families' current situations.  
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3 **Design** Interviews with open questions about the families' current pain  
4 situations were carried out by the first author. Interviews were audio recorded  
5 and transcribed, and subsequently analysed using descriptive content analysis.  
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9 **Setting** Urban and rural areas in two municipalities in Southern Norway.  
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11 **Participants** Parents of children with abdominal pain, who had been referred to  
12 a local hospital by their general practitioner and had been discharged without a  
13 somatic diagnosis. Fifteen parents of 14 children aged 8-17 years who had also  
14 been interviewed in 2016.  
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17 **Results** Nine of the children had recovered from their abdominal pain. During  
18 the pain period, the parents reported frustration with not having a diagnosis  
19 nor a specific treatment for their child's abdominal pain. The siblings in some  
20 families received less attention and were afraid that something serious might  
21 happen to their sister or brother. The parents wished that their child's school  
22 cared more about the child when they had weeks of absence. All parents  
23 maintained that their child's pain was physical, though they thought that  
24 psychological aspects might have influenced the symptoms. The parents stated  
25 that they as well as their children needed guidance from professionals to  
26 understand the complex pain situation.  
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## 52 **Strengths and limitations of this study**

- 53 • The main strength of the present study is that the complete cohort of  
54 parents who had been interviewed three years ago agreed to be  
55 interviewed again.  
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- A strength is also that the same researcher carried out all interviews on both occasions.
- The use of semi-structured interviews enabled detailed information about the parents' experiences over the three years.
- The sample size is small, and with one exception, only one of the parents in each family was interviewed.
- Only parents well integrated into the society were approached.

## INTRODUCTION

Functional gastrointestinal disorders (FGIDs) is a common diagnosis among children and adolescents with gastrointestinal tract symptoms who present to primary care physicians or gastroenterologists. The Rome criteria have become the standard for defining FGIDs, which are characterized by chronic or recurrent digestive symptoms without an underlying somatic disease or biochemical abnormality<sup>1</sup>. The diagnosis is based exclusively on symptoms reported by the children and the parents and the condition has no biological markers<sup>1</sup>.

In 1958, the British paediatrician John Apley published his pioneering research into children with abdominal pain, which was then called recurrent abdominal pain (RAP), this has now been replaced by FGIDs. Apley found that 11% of British schoolchildren had FGIDs and stated: "It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment"<sup>2</sup>. He was the first to establish criteria to define FGIDs as a distinct syndrome<sup>3</sup>.

Complaints of chronic abdominal pain occur in 10-19% of children, with prevalence highest in children aged four to six years and in early adolescence<sup>4</sup>.

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3 The prevalence rates of chronic abdominal pain among school-age children in  
4 the United States and Europe range from 0.3-19%<sup>5</sup>. In almost 90% of these  
5 children, no explanatory organic cause can be identified<sup>6</sup>. There are no  
6 significant differences in FGIDs related to sex, race or ethnic groups, except in  
7 functional constipation, which is significantly more prevalent in males  
8 compared to females<sup>7</sup>. There is overlap between parental and child FGIDs  
9 symptoms. Children with FGIDs report a lower quality of life compared to  
10 healthy children<sup>7</sup>.

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20 The child's or adolescent's and their family's life quality are negatively  
21 impacted by chronic abdominal pain. Families of children with chronic pain  
22 generally have poorer family functioning than do healthy populations. Pain-  
23 related disability is more consistently linked to family function than to pain  
24 intensity<sup>8</sup>. Research has demonstrated that parents of children with chronic  
25 pain also experience negative mental and social outcomes<sup>9</sup>. Understanding the  
26 cause of the pain seems to be important for recovery, and parents tend to be  
27 open to psychosocial interventions for their child's pain, such as stress  
28 reduction or relaxation exercises and want to discuss both physical and  
29 psychological etiological factors and treatment opinions<sup>10</sup>. Difficulties within  
30 the family may increase the child's pain, which may, in turn, negatively affect  
31 the parents and family life<sup>11</sup>. Young people with chronic pain and their parents  
32 often experience uncertainty about the diagnosis, which may be linked to their  
33 acceptance of it and response to treatment<sup>12</sup>. Parents frequently state that  
34 they feel helpless when faced with their child's suffering. These fears and  
35 worries may explain why parents reinforce illness behaviours by showing  
36 empathy for an apparently sick child<sup>13</sup>.

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In a study published in 2018, we carried out interviews with parents of  
14 children with chronic abdominal pain who had been discharged from the

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3 hospital without a somatic explanation<sup>14</sup>. The study concluded that functional  
4 pain in children and adolescents is challenging for the patient and the family  
5 and that they often need medical support for a long period. Three years after  
6 the first interviews, we wanted to learn how these the children and their  
7 families were progressing, by again interviewing the parents. By following  
8 these families over some years, we could gain valuable information about the  
9 children's symptoms and treatment. To our knowledge, a follow-up qualitative  
10 study such as this has previously not been conducted in this patient group.  
11 Thus, our aim was to investigate the course of the child's abdominal pain, what  
12 may have helped, how the family's situation had been influenced, and whether  
13 they had any unmet needs.  
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## 29 **METHODS**

### 30 *Participants*

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34 In 2016, the first author carried out an interview study with 15 parents of 14  
35 children with chronic abdominal pain<sup>14</sup>. She deliberately aimed at a broad age  
36 span (from 5 to 15 years), and the children included were between 6 and 13.5  
37 years old. All had been referred to a hospital in a medium-sized Norwegian city  
38 that serves around 500 000 inhabitants. The child's general practitioner (GP)  
39 had not found an explanation for the abdominal pain, and subsequent hospital  
40 investigations had not revealed any specific pathology. The only exclusions  
41 criterion was an inability to communicate in the Norwegian language.  
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51 Recruitment was carried out consecutively face to face among eligible families  
52 by a nurse at the hospital. After 14 interviews, data saturation had been  
53 reached and recruitment stopped. Details about the original recruitment  
54 process are given in our previous article<sup>14</sup>. The parents also agreed to be  
55 invited to an interview again in three years. In 2019, the first author contacted  
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3 the parents by telephone and arranged an interview meeting. All parents  
4 accepted the invitation. As in 2016, a qualitative design with individual  
5 interviews was used.  
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### 11 *Interviews*

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15 The parents were interviewed by the first author, a female GP who is also a  
16 child and adolescent psychiatrist and works at the hospital's child psychiatric  
17 department. The parents knew that the interviewer was a physician; in the  
18 interview setting, however, she presented herself as a researcher with a special  
19 interest in FGIDs, but with no therapeutic responsibility. The interviewer was  
20 empathetic, though neutral, and encouraged the parents to speak freely. The  
21 interviews took place in locations that suited the parents: usually at the  
22 interviewer's office or at the parents' workplaces, with no-one else present.  
23 Four interviews were conducted by phone because the parents had moved or  
24 were on vacation. Each interview lasted 30-60 minutes. A semi-structural  
25 interview guide was used by the author, but not provided to the participants  
26 (Figure 1). The first author audio recorded and transcribed the interviews. The  
27 transcripts were not returned to the participants for comments.  
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### 46 *Data analysis*

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48 Qualitative content analysis was conducted based on work by Graneheim and  
49 Lundman<sup>15</sup>. Both authors read the transcripts individually and worked together  
50 on their analysis to achieve a common understanding and to reinforce the level  
51 of trust and credibility<sup>15</sup>. The transcripts were read several times. The text was  
52 sorted into meaning units, shortened and coded. These codes were then sorted  
53 into categories and sub-categories. From the categories, three main themes  
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3 emerged. No software tool was used for the analyses. The authors discussed  
4 the codes, categories and themes until agreement was reached. The themes  
5 were derived from the data, not identified in advance.  
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### 10 11 *Patient and public involvement*

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13 No patients involved.  
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## 20 **RESULTS**

### 21 *Participant and child information*

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23 In total, 15 parents of 14 children were interviewed - nine mothers, four  
24 fathers, and one couple. Ten of the parents were ethnic Norwegians. Four were  
25 of foreign origin but had lived in Norway for several years and spoke  
26 Norwegian fluently. All but two parents currently cohabitated with their child's  
27 other parent. In 2016, the interviewed children, seven boys and seven girls,  
28 were 6-13.5 years old; during the present study they were 9-17 years old.  
29 Thirteen children had siblings; nine had one sibling, two had two siblings, and  
30 two had three siblings.  
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### 44 *Current status of the children's abdominal pain*

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46 In the three years since the original interview, nine of the children had  
47 recovered from abdominal pain, and in three of them the pain persevered. In  
48 two of the children, the situation was unclear (Table 1). "Recovered" was  
49 defined as no subjective complaints and return to school and other activities.  
50 The boys and the girls who had recovered ranged in age from 10.5-17 years and  
51 8.8-15 years, respectively. The three children who still had pain were 9, 10 and  
52 11.5 years old.  
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Table 1: Current status of the children's abdominal pain

	Total number	Girls	Boys
Recovered	9	4	5
Still symptoms	3	1	2
Unsure situation	2	2	0

We identified three main themes:

1. Family burden and frustration - and how school issues implied a major dilemma.
2. The consequences of improvement.
3. Desire for a diagnosis and for advice.

*Theme 1: Family burden and frustration - and how school issues implies a major dilemma*

Nearly all the parents reported that the child's pain had affected their family. Half of the children (three boys and four girls) had been absent from school, six of them had missed several weeks. The parents had to stay home from work or arrange for a caregiver on these days. *"We tried to avoid being absent from work. The grandparents stayed with her. In the end I had to get a sick leave because she was at home for more than two months" (Interview No 14).*

Some parents had to stay with their child all day and night. The strain affected the family dynamics, and disrupted the normal daily life in the family, like having common meals and normal sleeping patterns. *"She was sick at night too. We became like zombies. We slept some hours each in her room. We ate in bed together with her" (Interview No 14).* Some parents feared that their worries could negatively affect the child. Not knowing the diagnosis and fear of

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3 serious illness influenced their everyday lives. *“My frustration spreads to him*  
4 *and so he reads me and I read him” (Interview No 2).*

### 9 *Effect on siblings*

10 Siblings’ reaction varied widely from not noticing the symptoms at all to being  
11 significantly affected. *“His big brother thinks he is a drama queen, that he*  
12 *exaggerates the symptoms” (Interview No 8).* In several of the families, younger  
13 siblings expressed difficulties with having an older brother or sister who  
14 experienced abdominal pain. The parents had less time to take care of the  
15 siblings. *“His little brother gets a little overlooked because his sister takes such*  
16 *a great pass. I myself as mother feel pity for him” (Interview No 4).*

17 Some of the siblings’ teachers had notices that the child was affected by the  
18 situation at home. *“He talked about his dark thoughts at home. That was tough*  
19 *for his little brother to hear. He got sad and his teacher noticed that. The*  
20 *atmosphere in the house was the worst” (Interview No 10).*

### 21 *The school situation – a major dilemma*

22 More than half of the parents were concerned about their child’s school  
23 situation and that the abdominal pain was influenced by problems there. Some  
24 reported that when the school situation got better, the child’s abdominal pain  
25 also recovered. *“She has started secondary school, started in a new class and is*  
26 *much better physically as well as psychologically” (Interview No 11).* The  
27 parents argued that children and adolescents were under a great deal of stress  
28 and that school contributed to this. Some worried that the school did not take  
29 the situation seriously. *“There is little communication with the school. We had*  
30 *hoped that the school had something to contribute. They knew about the*  
31 *problems, but did not take us seriously” (Interview No 11).*

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3 Some of the parents elaborated on their dilemma by sending the child to  
4 school on days with abdominal pain. They explained that they knew school  
5 attendance was compulsory and important for social relationships and for the  
6 treatment, yet it was problematic for the parents. They expressed fear of being  
7 poor parents by forcing their child to go. *“They told us at the hospital that she  
8 should try to go to school again. But I told them it will not be possible for me to  
9 send her to school when she has pain” (Interview No.14).*

### 20 *Theme 2. The consequences of improvement*

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22 Nine of the 14 children (five boys and four girls) had recovered by the time of  
23 the follow-up interview. For six of these, the parents did not know the reason  
24 for the child’s recovery. Three of the children had been helped by treatments  
25 for constipation and reflux symptoms. One parent explained: *“The pain  
26 disappeared, the child just grew out of it” (Interview No 7).* One parent  
27 wondered what the child meant by “stomach pain” because she did not appear  
28 to be in pain. *“She cannot define it more clearly herself. Is this real pain or is it  
29 more a feeling of “air in the guts? Could the pain be an excuse or cover other  
30 problems for the child”? (Interview No 13).*

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41 Recovery from abdominal pain influenced the families and made the  
42 situation better for all family members. *“Her mood is much better now, so that  
43 makes it easier for her siblings and I can lower my shoulders” (Interview No 1).*  
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48 The children did not want their parents to worry; in turn, the parents  
49 wondered whether their children answered their questions accurately or hid  
50 their symptoms. They also wondered how this long pain period would affect  
51 the child’s development. *“This stomach pain has lasted several years. What will  
52 this do to him as a person? How will he be as an adult”? (Interview No 1).*  
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3 *Theme 3: Desire for a diagnosis and for advice*  
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5 Some of the parents emphasized that getting a diagnosis had made the child  
6 better. *“He was terrified, had stomach pain all the time and did not understand*  
7 *why. It helped him a lot to get the diagnosis and know that we could do*  
8 *something about it” (Interview No 10).* A diagnosis was also important to the  
9 parents. The discussion about when to stop pursuing further examinations to  
10 find a diagnosis was difficult. To stop investigations before the child had a  
11 diagnosis seemed not acceptable. *“We are so desperate about the pain*  
12 *situation. I am fully aware of the academic foundation that it is expensive and*  
13 *takes resources, but as a parent it would have calmed me down” (Interview No*  
14 *1).*

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27 The follow-up from the hospital was reported as frustrating by some of  
28 the parents *“I want more co-operation between patient/parents and hospital, it*  
29 *would have made the treatment more effective. it is important to look at the*  
30 *whole story, all factors together”.* (Interview No 10). The parents reported  
31 having been told that “it is up to you to try” and they missed guidance over time  
32 by a doctor or nurse.

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39 All the parents thought, as they did in 2016, that the abdominal pain was  
40 a physical condition. However, some also thought that there could be  
41 psychological factors (such as school problems, problems with friends etc.) that  
42 affected the pain. Four of the children had talked to a child and adolescent  
43 psychologist, another one parents had asked for that type of appointment, but  
44 their request was not fulfilled. Two children sought guidance from a family  
45 member with psychological expertise. Two parents reported that their child did  
46 not need to talk to a psychologist.  
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## DISCUSSION

Fifteen parents of 14 children with FGIDs, who had been discharged from hospital without an identified somatic cause were interviewed in 2016 and again for the present study in 2019. During the intervening years, nine children had recovered from their abdominal pain. For six of these, no reason for their recovery had been identified. The parents reported frustration with not having a somatic diagnosis for their child, they missed having closer contact with a doctor and cooperation with school was poor. All parents maintained that their child's pain was physical, though they thought that psychological aspects might have influenced the symptoms. The parents thought it was impossible and inhumane to force the child to school on days with pain.

Previous studies have stated the importance of school also in pain periods<sup>16,17</sup>. According to a study by Lowth and coauthors, parents should be advised to reduce concerned responses to their child's pain, focusing on distraction instead<sup>16</sup>. Walker et al state that the abdominal pain may be related to separation anxiety, and that parents' role and mindset need to be changed from protecting the child from possible harm to being a coach to encourage and support the child to engage in normal activities<sup>17</sup>. The goal of treatment thus will be return to normal activities, rather than removing pain. The parents in the current study wanted a closer co-operation with school and believed that it was a prerequisite for successful treatment. However, they emphasized that this was complicated and frustrating. This makes psychoeducation and support to these families over time an important part of the treatment<sup>16</sup>. Some parents worried about the impact of long-term pain on their child's development. This topic has been discussed in others studies<sup>18</sup>. The child's possibility to a successful stepping forwards into adult life also must be an aspect of the treatment<sup>18</sup>.

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3 In families with more than one child, the parent's tasks seem complex, as  
4 they need to care for both the child with abdominal pain and the siblings.  
5 Parents with chronically ill children have been described to live in a never-  
6 ending battle, which is challenging for the whole family <sup>19</sup>. It is known that  
7 siblings of children with FGIDs have significantly higher mean levels of  
8 emotional and/or behavioral symptoms compared with siblings of comparable,  
9 healthy children <sup>20</sup>. The siblings' involvement in our study ranged from very  
10 serious concerns to not caring.  
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20 Michael Balint wrote about the concept of "the child as the presenting  
21 symptom" <sup>21</sup>. When a child was repeatedly taken to see a GP, it was often  
22 found that the parents also needed therapy, usually of an emotional,  
23 psychological nature. These families often seem vulnerable to being  
24 misunderstood and misinterpreted. Consequently, their doctors should be both  
25 agile and clear with treatment recommendations <sup>21</sup>. Simultaneously, a study  
26 from 2018 showed that the parents were highly strained due to the demands  
27 of their role as caregivers to a child with functional abdominal pain <sup>22</sup>. The  
28 parents' behavior can be seen as operant factors that serve to either increase or  
29 decrease adaptive child behavior <sup>23</sup>. This concern was also raised by the  
30 participants in our study, as some parents raised the question of whether their  
31 worries about their child's symptoms might impact the child and maintain their  
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48 It is important to both exclude organic causes and to identify eventual  
49 positive indications of emotional problems <sup>24</sup>. Crushell et al. found that only  
50 one in 14 parents of children with ongoing pain believed that there was a  
51 psychological cause for their child's pain <sup>25</sup>. All our respondents believed their  
52 child's abdominal pain had physiological causes, although some thought  
53 psychological aspects could influence the symptoms. These expressions could  
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3 explain why so few of the children had spoken to a psychologist. Nevertheless,  
4 is it important to include psychological therapy such as cognitive behavior  
5 therapy in the treatment plan <sup>16</sup>. Psychological interventions for managing  
6 paediatric chronic pain have involved the parents in treatment using this  
7 approach, i. e. teaching the parents techniques to increase adaptive child  
8 behaviour such as rewarding the child's school attendance <sup>24</sup>. Parents'  
9 problem-solving methods overall, not just regarding health problems, usually  
10 affect their children. The adults in a family are, in most cases, the child's role  
11 models. Palermo reported that parents' emotions, behaviours, and health play  
12 a role in children's pain experiences <sup>26</sup>.

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14 The expression "grew out of the pain" was used by six of the 14 parents in  
15 our study. A study from 2020 also stated that most children do not have  
16 persistent symptoms throughout childhood <sup>27</sup>. Our participants seemed to be  
17 satisfied with this solution and had no further need for more detailed knowledge.  
18 The parents in our study reported in both interviews (i.e.in 2016 and again in  
19 2019) that it was frustrating not having a diagnosis. To deal with the abdominal  
20 pain became difficult when the diagnosis was uncertain. Having had somebody  
21 to talk to about the pain or being provided with an explanation from the doctor  
22 would have made the situation better. Several studies reveal a clear desire by  
23 parents for information about the causes of their child's pain, treatment  
24 options available, and for effective strategies to enhance their child's ability to  
25 cope with pain <sup>16,20,28</sup>..

### 26 27 28 *Strengths and limitations*

29 The first author and interviewer is a GP and a child and adolescent psychiatrist.  
30 When conducting the interviews, she presented herself as a researcher, to  
31 emphasize that she had no therapeutic responsibilities in this setting and that



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3 the parents could speak freely. We expect that this improved both the  
4 interview quality and interpretation. The interview participants were mainly  
5 ethnic Norwegians, other ethnic groups might have responded differently.  
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## 10 11 **Conclusion**

12 A child having functional pain is challenging for the child as well as the parents  
13 and siblings. The goal of the treatment is helping the child and the family to  
14 return to normal function, like attending school and other activities. This  
15 underlines the importance of psychoeducation about the symptoms and pain  
16 treatment strategies. Cognitive behaviour therapy or other psychological  
17 interventions may help the families, and follow-up over time by a trusted  
18 physician is essential.  
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## 30 31 **Author contribution**

32 Both authors planned the study. MB applied for ethics approval. AB carried out  
33 the interviews and transcribed the text, and both authors participated in the  
34 analyses. AB drafted the article, and MB revised it critically.  
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## 40 41 **Ethics approval**

42 The Regional Committees for Medical and Health Research Ethics approved the  
43 study (reference no. 2019/646). The study has followed the operational  
44 principles of the Declaration of Helsinki and adhered to the Belmont Report  
45 principles (i.e. respect for persons; beneficence; and justice) in obtaining valid  
46 informed consent from parents.  
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50 The parents gave written consent to participate. Even when only one of the  
51 parents was interviewed both parents signed the declaration of consent. The  
52 children and adolescents were informed about the study through an  
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3 information letter, and children 16 years or older provided a written consent  
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5 stating that their parent(-s) could participate.  
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10 **Disclosure statement**

11 The authors report no conflicts of interests.  
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16 **Acknowledgement**

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18 We are grateful to all parents sharing their experiences with us.  
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23 **Funding statement**

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25  
26 Research in General Practice. Grant number N/A.  
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31 **Data availability statement**

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33 The data are deidentified interviews transcribed in full text. No data are  
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35 available.  
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6 [children-and-adolescents-management-in-primary-care?\(Accessed on](https://www.uptodate.com/contents/functional-abdominal-pain-in-children-and-adolescents-management-in-primary-care?(Accessed%20on%20December%202019))  
7 [December 2019\)](https://www.uptodate.com/contents/functional-abdominal-pain-in-children-and-adolescents-management-in-primary-care?(Accessed%20on%20December%202019))  
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14 **Figure legend figure 1**

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17 Understanding parents' experiences of disease course and influencing  
18 factors: A three-year follow-up qualitative study among parents of  
19 children with functional abdominal pain – interview guide.  
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## Figure 1 Interview guide

1. Concerning the stomach pain – how is your child doing at present?
2. Concerning the stomach pain – how has the situation been during the last 3 years?  
For the child? For the family?
3. How has the child's pain affected the family? Parents? Siblings?
4. How has improvement or worsening of the pain affected the family?
5. Has the child been followed up by a GP or by the hospital during the last 3 years?
6. Has the child seen any other health personnel?
7. What do you think has contributed to the child's improvement/worsening?
8. Is there anything more I should have asked?
9. How did you experience this interview?

## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**