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

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Key words: Paediatrics, General Practice, Gastroenterology, Pain

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 [1]. The diagnosis is based exclusively on symptoms reported by the children and the parents and the condition has no biological markers of the condition [1].

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” [2]. He was the first to establish criteria to define FGIDs as a distinct syndrome [3].

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 [4].

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

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

In a study published in 2016, we carried out interviews with the parents of 14 children with chronic abdominal pain who had been discharged from the hospital without a somatic explanation [14]. Three years after the first interviews, we wanted to learn how these the children and their families were progressing, by again interviewing the parents. To our knowledge, a follow-up study such as this has not been previously conducted. 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 [14]. At that time, the children were 5-15 years old and 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 parents had agreed to be interviewed again in three years. In 2019, the first author contacted the parents and arranged an interview meeting. All parents accepted the invitation. The only exclusions criterion was an inability to communicate in the Norwegian. As in 2016 a qualitative design with individual interviewer was used and a semi-structural interview guide was developed by the research team.

Interviews

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

Data analysis

The first author audio recorded and transcribed the interviews. Qualitative content analysis was conducted based on work by Graneheim and Lundman [15]. Both authors read the transcripts individually and worked together on their interpretation to achieve a common understanding and to reinforce the level of trust and credibility [15].

The transcripts were read several times. The text was sorted into meaning units, shortened and coded. These codes were then sorted into categories and sub-categories. From the categories, three main themes emerged.

Patient and public involvement

No patients involved.

RESULTS

Participant and child information

In total, 15 parents of 14 children were interviewed - nine mothers, four fathers, and one couple. Ten of the parents were ethnic Norwegians. Four were of foreign origin but had lived in Norway for several years and spoke Norwegian fluently. All but two parents currently cohabitated with their child's other parent.

In 2016, the interviewed children, seven boys and seven girls, were 5-15 years old; during the present interviews they were 8-18 years old. Thirteen 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 of them had missed several weeks. The parents had to stay home from work or arrange for a caregiver on these days. *"It is a mental strain, especially the absence from work" (Interview No 8).*

"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. *"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).*

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

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

Effect on siblings

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

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

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

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

Parents' worries about their child

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

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

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

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

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

The whole situation is better for all now that the diagnosis is known" (Interview No 6).

The children did not want their parents to worry, in turn the parents wondered whether their children answered questions accurately or hid their symptoms. They also wondered how this long pain period would affect the child's development. *"This stomach pain has lasted several years. What will this do to him as a person? How will he be as an adult"? (Interview No 1).*

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 had contact with a family member with psychological expertise. Two parents reported that their child did not need to talk to a psychologist.

Theme 3: What were the families' present needs?

Desire for a diagnosis

Some of the parents emphasized that getting a diagnosis had made the child better.

"He was terrified, had stomach pain all the time and did not understand why. It helped him a lot to get the diagnosis and know that we could do something about it" (Interview No 10).

A diagnosis was important to the parents. The discussion about when to stop pursuing further examinations in pursuit of a diagnosis was difficult. *"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).*

Some of the parents reported frustration with the follow-up from the hospital. *"We want a more specific feedback and more information from the doctor. I have to be a nutritionist myself to help my child"* (Interview No 13).

"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).

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 child's symptoms. The parents also reported that the whole family was affected by the child's abdominal pain.

Some of the children had days, or even weeks, when they were absent from school. On these days, the parents or grandparents stayed home from work to look after the child. Lowth reported that parents should be advised to reduce concerned responses to their child's pain, focusing on distraction instead. Children should attend school irrespective of pain. This can be initially difficult, however, progress is often rapid [16]. Making the child attend school was often very hard for parents in the current study. They felt that doing so was inhumane, which led to family discussions. Parents need much support to be consistent in following-up with their child. Walker et al wrote "The parent's role and mindset must change. Until now, the parent's job was to protect the child from possible harm while searching for a cause of the pain. Emphasize that the parent's job now is to be a "coach", to encourage and support the child's return to normal activities. Even children with organic disease — such as diabetes or cystic fibrosis attend school" [17].

The pain topic could also tie the family together, as a problem they have in common and on which they must cooperate. Sjøgård wrote: "Parents with a chronically ill child live in a constant battle. A never-ending battle between something good and bad. To live with a chronically ill child is challenging for the whole family" [18]. Siblings of children with FGIDs have been reported to have significantly higher mean levels of emotional and/or behavioural symptoms compared with the siblings of comparable, healthy children [19]. In families with more than one child the parents' tasks seem complex, needing to care for both the child with pain and their siblings.

Some parents worried about the impact of long-term pain on their child's development. Reid et al wrote: "This raises questions about the long-term impact of persistent chronic pain on children's development and success stepping forward into adulthood. This is an important topic for future research."[20] Michael Balint wrote about the concept of "the child as the presenting symptom" [21] . When a child was repeatedly taken to see a GP, it was often found that the parent also needed therapy, usually of an emotional, psychological nature. These families often seem vulnerable to being misunderstood and misinterpreted. Consequently, their doctors should be both agile and clear with treatment recommendations.[21] Some of the parents in our study raised the question of whether their worries about their child's symptoms might impact the child and maintain their pain. Palermo stated "The parent's behavior is conceptualized as operant factors that serve to either increase or decrease adaptive child behavior" [22]. Lask et al. conclude that it is important to both exclude organic causes and to identify positive indications of emotional problems. Careful explanation and patient discussion with the parents are both essential [23]. These authors also use the expression "grew out of it "[23]. The parents in our study had similar conclusions regarding six of the 14 children.

In our study all the parents believed their child's abdominal pain had physiological causes, although some thought psychological aspects could impact the symptoms. Crushell et al. found that only one in 14 parents of children with ongoing pain believed that there was a psychological cause for their child's pain [24]. Psychological interventions for managing paediatric chronic pain have involved the parents in treatment using this approach, (i. e. teaching the parents techniques to increase adaptive child behaviour such as rewarding the child's school attendance) [23]. Parents' problem-solving methods-overall, not just regarding health problems, usually affect their children. The adults in a family are, in most cases, the child's role models. Palermo reported that parents' emotions, behaviours, and health play a role in children's pain experiences. [25].

Reid et al. stated that parents' responses demonstrate a clear desire for information about the causes of their child's pain, treatment options available at the pain clinic, effective strategies to enhance their child's ability to cope with pain, and the effects of pain on both the child's body and mood [20]. The parents in our study reported in both interviews (i.e.in 2016 and again in 2019) that it was frustrating not having a diagnosis. Treatment of the abdominal pain became difficult when the diagnosis was uncertain. The parents felt that they had to be "a nutritionist themselves" and had to give their child food advice. They worried that the child could have a serious diagnosis. Having had somebody to talk to about the pain or being provided with an explanation from the doctor would have made the situation better. In addition, an appointment with a psychologist would have made the situation easier. Although two parents stated that their child did not need a psychologist, there was a positive attitude among the other parents about having a psychologist on the treatment team. Lowth stated "The most important therapeutic step is to explain the diagnosis, explain strategies to cope with stress and provide reassurance that there is no serious underlying disease" [16].

Many of the parents were concerned about school. They wanted close co-operation with their child's school and expressed that this was a prerequisite for successful treatment. Returning to school is an important part of helping a child with functional pain to improve. The goal of treatment is a return to normal activities, rather than removing pain.

Strengths and limitations

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

Conclusion

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

Author contribution

Both authors planned the study. MB applied for ethics approval. AB carried out the interviews and transcribed the text, and both authors participated in the analyses. AB drafted the article, and MB revised it critically.

Ethics approval

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

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

Disclosure statement

The authors report no conflicts of interests.

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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

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?

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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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.

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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 [1]. The diagnosis is based exclusively on symptoms reported by the children and the parents and the condition has no biological markers [1].

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" [2]. He was the first to establish criteria to define FGIDs as a distinct syndrome [3].

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

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

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 [14]. 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 [14]. 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 by a nurse at the hospital. After 14 interviews, data saturation had been reached and recruitment stopped. Details about the original recruitment process are given in our previous article [14]. The parents also agreed to be invited to an interview again in three years. In 2019, the first author contacted the parents by telephone and arranged an interview meeting. All parents accepted the invitation. As in 2016, a qualitative design with individual interviews was used.

Interviews

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

Data analysis

Qualitative content analysis was conducted based on work by Graneheim and Lundman [15]. Both authors read the transcripts individually and worked together on their analysis to achieve a common understanding and to reinforce the level of trust and credibility [15]. The transcripts were read several times. The text was sorted into meaning units, shortened and coded. These codes were then sorted into categories and sub-categories. From the categories, three main themes emerged. No software tool was used for the analyses. The authors discussed the codes, categories and themes until agreement was reached. The themes were derived from the data, not identified in advance.

Patient and public involvement

No patients involved.

RESULTS

Participant and child information

In total, 15 parents of 14 children were interviewed - nine mothers, four fathers, and one couple. Ten of the parents were ethnic Norwegians. Four were of foreign origin but had lived in Norway for several years and spoke Norwegian fluently. All but two parents currently cohabitated with their child's other parent. In 2016, the interviewed children, seven boys and seven girls, were 6-13.5 years old; during the present study they were 9-17 years old. Thirteen 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, nine of the children had recovered from abdominal pain, and in three of them the pain persevered. In two of the children, the situation was unclear (Table 1). "Recovered" was defined as no subjective complaints and return to school and other activities. The boys and the girls who had recovered ranged in age from 10.5-17 years and 8.8-15 years, respectively. The three children who still had pain were 9, 10 and 11.5 years old.

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

Effect on siblings

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

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

The school situation – a major dilemma

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 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 worried that the school did not take the situation seriously. *"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).*

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

Theme 2. The consequences of improvement

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

Recovery from abdominal pain influenced the families and made the situation better for all family members. "*Her mood is much better now, so that makes it easier for her siblings and I can lower my shoulders" (Interview No 1).* The children did not want their parents to worry; in turn, the parents wondered whether their children answered their questions accurately or hid their symptoms. They also wondered how this long pain period would affect the child’s development. *“This stomach pain has lasted several years. What will this do to him as a person? How will he be as an adult”? (Interview No 1).*

Theme 3: Desire for a diagnosis and for advice

Some of the parents emphasized that getting a diagnosis had made the child better. *“He was terrified, had stomach pain all the time and did not understand why. It helped him a lot to get the diagnosis and know that we could do something about it” (Interview No 10).* A diagnosis was also important to the 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).*

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.

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 member with psychological expertise. Two parents reported that their child did not need to talk to a psychologist.

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.

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 [16,17]. The parents should be advised to reduce concerned responses to their child's pain, focusing on distraction instead [16]. The 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 [17] . 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 [16] . Some parents worried about the impact of long-term pain on their child's development. This topic has been discussed in others studies [18]. The child's possibility to a successful stepping forwards into adult life also must be an aspect of the treatment [18] .

In families with more than one child, the parent's tasks seem complex, as they need to care for both the child with abdominal pain and the siblings. Parents with chronically ill children have been described to live in a never-ending battle, which is challenging for the whole family [19]. It is known that siblings of children with FGIDs have significantly higher mean levels of emotional and/or behavioral symptoms compared with siblings of comparable, healthy children [20]. The siblings' involvement in our study ranged from very serious concerns to not caring.

Michael Balint wrote about the concept of "the child as the presenting symptom" [21]. When a child was repeatedly taken to see a GP, it was often found that the parents also needed therapy, usually of an emotional, psychological nature. These families often seem vulnerable to being misunderstood and misinterpreted. Consequently, their doctors should be both agile and clear with treatment recommendations [21]. Simultaneously, a study from 2018 showed that the parents were highly strained due to the demands of their role as caregivers to a child with functional abdominal pain [22]. The parents' behavior can be seen as operant factors that serve to either increase or decrease adaptive child behavior [23]. This concern was also raised by the participants in our study, as some parents raised the question of whether their worries about their child's symptoms might impact the child and maintain their pain

It is important to both exclude organic causes and to identify eventual positive indications of emotional problems [24]. Crushell et al. found that only one in 14 parents of children with ongoing pain believed that there was a psychological cause for their child's pain [25]. All our respondents believed their child's abdominal pain had physiological causes, although some thought psychological aspects could influence the symptoms. These expressions could explain why so few of the children had spoken to a psychologist. Nevertheless, is it important to include psychological therapy such as cognitive behavior therapy in the treatment plan [16]. Psychological interventions for managing paediatric chronic pain have involved the parents in treatment using this approach, i. e. teaching the parents techniques to increase adaptive child behaviour such as rewarding the child's school attendance [24]. Parents' problem-solving methods overall, not just regarding health problems, usually affect their children. The adults in a family are, in most cases, the child's role models. Palermo reported that parents' emotions, behaviours, and health play a role in children's pain experiences [26].

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

Strengths and limitations

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

Conclusion

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

Author contribution

Both authors planned the study. MB applied for ethics approval. AB carried out the interviews and transcribed the text, and both authors participated in the analyses. AB drafted the article, and MB revised it critically.

Ethics approval

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

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

Disclosure statement

The authors report no conflicts of interests.

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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.
Domain 1: Research team and reflexivity			
Personal characteristics			
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?	
Relationship with participants			
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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
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?	
Setting			
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	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views 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 inter view or focus group?	
Duration	21	What was the duration of the inter views 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?	
Domain 3: analysis and findings			
Data analysis			
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?	
Reporting			
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

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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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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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Key words: Paediatrics, General Practice, Gastroenterology, Pain

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.

c

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 [1]. The diagnosis is based exclusively on symptoms reported by the children and the parents and the condition has no biological markers [1].

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" [2]. He was the first to establish criteria to define FGIDs as a distinct syndrome [3].

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 [4].

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

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

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 [14]. 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 [14]. 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 around 500 000 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 by a nurse at the hospital. After 14 interviews, data saturation had been reached and recruitment stopped. Details about the original recruitment process are given in our previous article [14.] The parents also agreed to be invited to an interview again in three years. In 2019, the first author contacted the parents by telephone and arranged an interview meeting. All parents accepted the invitation. As in 2016, a qualitative design with individual interviews was used.

Interviews

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

Data analysis

Qualitative content analysis was conducted based on work by Graneheim and Lundman [15]. Both authors read the transcripts individually and worked together on their analysis to achieve a common understanding and to reinforce the level of trust and credibility [15]. The transcripts were read several times. The text was sorted into meaning units, shortened and coded. These codes were then sorted into categories and sub-categories. From the categories, three main themes emerged. No software tool was used for the analyses. The authors discussed the codes, categories and themes until agreement was reached. The themes were derived from the data, not identified in advance.

Patient and public involvement

No patients involved.

RESULTS

Participant and child information

In total, 15 parents of 14 children were interviewed - nine mothers, four fathers, and one couple. Ten of the parents were ethnic Norwegians. Four were of foreign origin but had lived in Norway for several years and spoke Norwegian fluently. All but two parents currently cohabitated with their child's other parent. In 2016, the interviewed children, seven boys and seven girls, were 6-13.5 years old; during the present study they were 9-17 years old. Thirteen 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, nine of the children had recovered from abdominal pain, and in three of them the pain persevered. In two of the children, the situation was unclear (Table 1). "Recovered" was defined as no subjective complaints and return to school and other activities. The boys and the girls who had recovered ranged in age from 10.5-17 years and 8.8-15 years, respectively. The three children who still had pain were 9, 10 and 11.5 years old.

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

Effect on siblings

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

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

The school situation – a major dilemma

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 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 worried that the school did not take the situation seriously. *“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).*

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

Theme 2. The consequences of improvement

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

Recovery from abdominal pain influenced the families and made the situation better for all family members. "*Her mood is much better now, so that makes it easier for her siblings and I can lower my shoulders" (Interview No 1).* The children did not want their parents to worry; in turn, the parents wondered whether their children answered their questions accurately or hid their symptoms. They also wondered how this long pain period would affect the child's development. *"This stomach pain has lasted several years. What will this do to him as a person? How will he be as an adult"? (Interview No 1).*

Theme 3: Desire for a diagnosis and for advice

Some of the parents emphasized that getting a diagnosis had made the child better. *"He was terrified, had stomach pain all the time and did not understand why. It helped him a lot to get the diagnosis and know that we could do something about it" (Interview No 10).* A diagnosis was also important to the 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).*

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.

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 member with psychological expertise. Two parents reported that their child did not need to talk to a psychologist.

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 [16,17]. 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 [16]. 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 [17] . 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 [16] . Some parents worried about the impact of long-term pain on their child's development. This topic has been discussed in others studies [18]. The child's possibility to a successful stepping forwards into adult life also must be an aspect of the treatment [18] .

In families with more than one child, the parent's tasks seem complex, as they need to care for both the child with abdominal pain and the siblings. Parents with chronically ill children have been described to live in a never-ending battle, which is challenging for the whole family [19]. It is known that siblings of children with FGIDs have significantly higher mean levels of emotional and/or behavioral symptoms compared with siblings of comparable, healthy children [20]. The siblings' involvement in our study ranged from very serious concerns to not caring.

Michael Balint wrote about the concept of "the child as the presenting symptom" [21]. When a child was repeatedly taken to see a GP, it was often found that the parents also needed therapy, usually of an emotional, psychological nature. These families often seem vulnerable to being misunderstood and misinterpreted. Consequently, their doctors should be both agile and clear with treatment recommendations [21]. Simultaneously, a study from 2018 showed that the parents were highly strained due to the demands of their role as caregivers to a child with functional abdominal pain [22]. The parents' behavior can be seen as operant factors that serve to either increase or decrease adaptive child behavior [23]. This concern was also raised by the participants in our study, as some parents raised the question of whether their worries about their child's symptoms might impact the child and maintain their pain

It is important to both exclude organic causes and to identify eventual positive indications of emotional problems [24]. Crushell et al. found that only one in 14 parents of children with ongoing pain believed that there was a psychological cause for their child's pain [25]. All our respondents believed their child's abdominal pain had physiological causes, although some thought psychological aspects could influence the symptoms. These expressions could explain why so few of the children had spoken to a psychologist. Nevertheless, is it important to include psychological therapy such as cognitive behavior therapy in the treatment plan [16]. Psychological interventions for managing paediatric chronic pain have involved the parents in treatment using this approach, i. e. teaching the parents techniques to increase adaptive child behaviour such as rewarding the child's school attendance [24]. Parents' problem-solving methods overall, not just regarding health problems, usually affect their children. The adults in a family are, in most cases, the child's role models. Palermo reported that parents' emotions, behaviours, and health play a role in children's pain experiences [26].

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

Strengths and limitations

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

Conclusion

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

Author contribution

Both authors planned the study. MB applied for ethics approval. AB carried out the interviews and transcribed the text, and both authors participated in the analyses. AB drafted the article, and MB revised it critically.

Ethics approval

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

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

Disclosure statement

The authors report no conflicts of interests.

Acknowledgement

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Data availability statement

The data are deidentified interviews transcribed in full text. No data are available.

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Figure legend figure 1

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

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.
Domain 1: Research team and reflexivity			
Personal characteristics			
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?	
Relationship with participants			
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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
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?	
Setting			
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	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views 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 inter view or focus group?	
Duration	21	What was the duration of the inter views 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?	
Domain 3: analysis and findings			
Data analysis			
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?	
Reporting			
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

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