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Parents' experience when their child has chronic abdominal pain—a qualitative study in Norway

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Parents' experience when their child has chronic abdominal pain—a qualitative study in Norway

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Running head:

Parents' experience of their child in chronic pain

Article category:

Research article

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Parents' experience when their child has chronic abdominal pain—a qualitative study in Norway

ABSTRACT

Objective Functional abdominal pain occurs frequently in children and adolescents. It is an exclusion diagnosis; somatic diseases have to be ruled out. However little explanation is given for why the youngster is experiencing pain. The aim was to explore the experiences of parents of children with chronic abdominal pain discharged from hospital without a somatic explanation.

Design The study has a qualitative design. The open questions concerned pain experiences and management. Interviews were conducted at the hospital, at the parents' workplace or in their homes, audiotaped and transcribed. A descriptive content analysis was used to analyze the transcribed text.

Setting Parents to children referred from general practice located in urban and rural areas in two municipals in Norway.

Participants 14 parents of children with functional abdominal pain aged 5–15 years.

Results Fourteen parents participated. Some explained that their child's disability glued the parents together on a common project to help the child. Other parents could tell that siblings got less attention and complained about too much alertness during pain. Parents wished for diagnosis that could be treated efficiently. Some were still anxious that an undetected condition triggered pain. They promoted their doctor to do further examinations. However, some parents knew that social factors could inflict pain, and that sensation like anxiety and "butterfly" tensions need interpretations different from pain. A professional guidance towards the child and parents on how to manage pain was much wanted.

Conclusion A diagnosis of functional abdominal pain should not be the final outcome of a doctors' consultation. Doctors may help these families further by focusing on pain management strategies.

Key words:

Child health, Chronic abdominal pain, Parents, Family, Primary Health Care, Qualitative Research

Strength and limitation

- Parents to children with chronic abdominal pain felt confused when their child was discharged from hospital without a somatic explanation: They were still convinced that something was undiscovered, and felt that they were left with the responsibility to solve the case.
- These parents wished for a doctor who could support the child as well as the parents in future pain management. The focus should change from finding the needle in the haystack to how to live with the pain.
- This study is confined to a small sample of informants, however we feel safe that it has relevance for general practice in common.

INTRODUCTION

In 1958, John Apley [1], a British paediatrician, published his pioneering research in children with abdominal pain, which he labelled recurrent abdominal pain (RAP) syndrome. He found that 10.8% of British schoolchildren had RAP and stated, 'It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment'. Since then, the term RAP has been replaced by functional gastrointestinal disorders (FGIDS) as defined by the Rome criteria.[1] FGIDS is characterized by chronic or recurrent digestive symptoms without an underlying somatic disease or biochemical abnormality. There are no biological markers of the condition, and the diagnosis is based exclusively on the symptoms reported by the child and parents.[2] The Rome criteria have become an influential standard for defining FGIDS, which is the most common diagnosis among patients with gastrointestinal tract symptoms who consulted gastroenterologists and primary care physicians.

Bonilla and Sapps [3] found that 38% of American schoolchildren and 35% of Columbian children reported weekly abdominal pain. A cross-sectional survey conducted in a school in Sri Lanka identified FGIDS in 28% of the children.[3] The prevalence rates of chronic abdominal pain among school-going children in the United States and Europe range from 0.3–19.0%.[4] In almost 90% of these children, no explanatory organic cause can be identified.[5] A study that reviewed the literature regarding the epidemiology of functional abdominal pain disorders in children found that they were a common problem worldwide.[6]

Chronic pain has a negative impact on the quality of life of children and adolescents, and of their families. Mothers feel restricted in their social life and have problems dealing with the stress of their adolescents' pain.[7] Chronic illness behaviour also appears to be learned.[8] Families of children with chronic pain generally have poorer family function than healthy populations. Pain-related disability is more consistently connected to family function than to pain intensity.[9] Difficulties in the family may increase the frequency of pain in children, and their pain may in turn affect their parents and family life.[10] Mothers of youngsters with functional abdominal pain were significantly more likely to have a lifetime history of irritable bowel syndrome, migraine, anxiety, depressive or somatoform disorders compared with other mothers.[11]

The treatment of paediatric abdominal pain should attempt to focus on the influence of the parents.[12] Parental responses to pain may be an important target for helping adolescents with their chronic pain.[13] Exclusion of organic disorders is important for making the diagnosis of FGIDS [14] after which it must be explained to the parents and the child that further examination will not change the diagnosis or the available treatment. However, this situation may trigger suspicion in parents and a feeling that the medical establishment has failed.

The aim of our study was to explore the experiences of parents of children with chronic abdominal pain who were discharged from hospital without a somatic explanation.

METHODS

A qualitative design with individual interviews was chosen. One aim is to condense single statements of experience into overarching concepts by text analysis of transcripts. By comparing comprehension by each researcher a common agreed understanding may be achieved.[15] A semi-structured interview guide was developed (Table 1) comprising 10 open-ended questions and additional follow-up questions that allowed the interviewer to probe more deeply.[16] The questions were developed after discussions and agreement within the interdisciplinary research team who all had experience with children and adolescent patients. After two interviews, the guide was evaluated and some small modifications were made.

Table 1. Interview guide

1. Could you tell about the last time your child had stomach pain?

2. How does your child react when he/she has stomach pain?

3. How do your spouse and the other children react when your child has stomach pain?

4. How do you experience the situation at home when your child has stomach pain?

5. Do you have some thoughts about the reason for your child's stomach pain?

6. What are you doing when your child has stomach pain?

7. How do you explain to your child about the stomach pain?

8. What did you experience last time you visited the hospital with your child?

9. You have told me they did not find anything physically wrong with your child at the hospital. How did you feel about that?

10. Could you please explain your feelings about the follow-up at the hospital when all tests were normal?

11. Which country do you and your family come from?

12. What is the tradition in the country you come from in managing pain? Any differences from Norway?

13. What could make you feel more secure about your child's stomach pain?

14. Is there anything more you would like to add concerning your child's stomach pain?

15. How did you experience this interview?

Recruitment

We recruited participants referred to a hospital located in a middle-sized Norwegian town that covers 440,000 inhabitants within the town and surrounding area.

A dedicated nurse at the outpatient department recruited parents to children aged 5-15 years old recently examined for recurrent abdominal pain.

She informed the parents about the study, handed out written information and obtained the phone number from those who wished to participate. The first author contacted the parents to arrange an interview. When fourteen interviews were completed, we did not identify new information and the recruitment was stopped.[17]

Interviews

The first author, who is a female GP and child- and adolescent psychiatrist, interviewed the parents. The parents knew that the interviewer was a physician; in the interview setting, however, she presented herself as a researcher with no therapeutic responsibility. The interviews were held in localities that suited the parents: in the family’s home, at the author’s office in the hospital, or at the parent’s work place. One interview was conducted by telephone. The interviews lasted 45–75 minutes. In one case both parents were present.

Data analysis

The interviews were audiotape recorded and transcribed by the first author. Qualitative content analysis was conducted based on Graneheim and Lundman.[16] All three 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.[16]

We read the transcripts several times. The texts were sorted into meaning units, shortened and coded. Then the codes were categorized into sub-categories and categories. From the categories, three main themes emerged.

RESULTS

Only two of the recruited parents lived without their spouse, and 10 of the interview subjects were Norwegian. Four foreign parents had lived in Norway for several years and mastered the language well. All, except for two parents, lived together. The children with abdominal pain were 6–13 years old (Table 2).

We identified three main themes: 1) the pain as a family project 2) the desire for a specific diagnosis and discussion with a professional, 3) interpreting and handling the child's pain.

Table 2. Characteristics of the families of interviewed parents

Sex of child with chronic abdominal pain	Age in years of the child with chronic abdominal pain	The parent interviewed; mother (M), father (F)	The birth order of the child with pain /total number of children in the family
Boy	8	M	
Boy	13	F	
Boy	7	M	
Boy	11	M	
Girl	6	M	
Girl	7	M+F	
Boy	8	F	
Girl	10	M	
Boy	6	M	
Girl	13	M	
Girl	6	F	
Girl	11	F	
Boy	13	M	
Girl	10	M	

The pain as a family project

Some parents reported that their child's pain affected the total family. The strength and duration of the pain seemed to be factors that partly decided the degree to which the family life was changed. Major changes in their lives could result, such as deciding to stay out of work and/or not prioritizing their social life: '*The whole family goes into another mode. We are around him and must adapt all our activities to him. We are thinking of this daily, every hour. It is the main subject of conversation between my wife and me*' (Interview 2). Other families had to make some small adjustments to their everyday life. In some families, there was no significant change even if the child had pain; their life went on more or less the same: '*He decides if he wants to eat or not, but I don't think it affects us much*' (Interview 3). The reactions among the siblings, reported by the parents, ranged from calling the index child a drama queen to not noticing the pain at all: '*The brother can be irritated sometimes, he thinks there is a lot of fuss about this (pain) and suspects that sometimes she is pretending*' (Interview 11). Some of the parents in our study recognized the symptoms and the child's situation because they had experienced the same stomach pain themselves. Most parents were worried about their child's situation and that it affected all family members much: '*I show a great deal of care, but it is very difficult. I get irritated sometimes but cannot show it. We hear complaints from him every day and it is so exhausting*' (Interview 13).

Desire for a specific diagnosis and desire for discussion with a professional

All parents considered that a physical condition caused their children's stomach-aches. However, some parents were aware that stress at school or difficulties with friends impacted the child, perhaps triggering or causing pain: '*Our opinion is that it could be several factors, it gets worse during periods with school- or other social problems*' (Interview 12). The parents reported frustration after their visits to hospital because they received no suggestions of ways to help the child. Parents expressed this annoyance differently: '*The doctors were good at informing us that these symptoms are not dangerous, but we know no more about the reasons for the pain. That is frustrating, but we must learn to live with it*' (Interview 2).

The goal for most parents was to receive a medical diagnosis leading to a treatment that would make their child pain free. Because this goal was not met, their child's pain continued to rule their daily life.

Since there were no external causes to the child's aches, the parents felt that something was wrong with their parenting. They were then in charge for helping their child without knowing what to do.

They felt to be blamed, which was experienced very humiliating: '*Yes, I am dictating to the doctors, telling them what kind of medicine he should have and that we want to come back to the hospital. I must take the responsibility for getting medical help*' (Interview 9). '*It is difficult and we despair because we do not know what we can do. If there had been a diagnosis, maybe it would have led to a treatment that would have helped. It is extremely sad and frustrating*' (Interview 3**).** The pain was an important topic in the conversations between the parents. They reported a wish to have a professional person for both the child and the parents to consult: '*It should be possible for parents who have children with chronic illnesses and no certain diagnosis to have a person to communicate with*' (Interview 2). '*The only thing they could help him with is that he would have someone to talk to, so that he would not keep everything inside himself* ' (Interview 13). Some parents wanted a quick fix or a healing tablet. They wanted their child to have further medical examinations, and that this should happen quickly: '*They could have examined more, because what if this is something very serious'?* (Interview 9). Some parents also hoped that a medicine would soon become available that could fix the symptoms: '*We hope that there will soon be a quick fix, a medicine that will solve the problem*' (Interview 2).

Interpreting and handling the child's pain

Parents often tried to teach their child what pain really is: '*Butterflies in the stomach is not the same as stomach pain, but she has a tendency to call everything stomach pain*' (Interview 5). When the child had days with severe pain, the parents dealt with the situation in different ways: '*She must go to the toilet; she is not getting any painkillers and she must learn to avoid the food she is reacting to'* (Interview 10). The parents reported that the sisters and brothers also showed different reactions. '*We all do not have so much to do with it. It is not so bad that we need to adapt our lives to this, but she must just learn to live with it*' (Interview 11). Some parents were afraid to be viewed as 'hysterical mothers'. They said that they understood that these thoughts and feelings were something they produced themselves, but they still feared not being taken seriously by the doctors. One parent reported that the child did not want to talk about the pain: '*He looks away, listens to YouTube, and he will not communicate with us. He puts on earplugs and lets the time flow away*' (Interview 2). Some families gathered to watch films or television together when the child had stomach pain because they felt that it drew the focus away from the pain: '*We skip sport or exercise that day, instead we relax at home together. We ask her what she wants to do, try to calm her down, watch a film together, play cards and try to distract her from the pain*' (Interview 8).

DISCUSSION

Parents of children with recurrent abdominal pain recently discharged from hospital without an identified somatic cause, felt frustrated because they did not receive specific help. They wanted a somatic explanation and a treatment that could solve the problem and alleviate their responsibility for a child in pain. They often reported that in a way, the child's condition focused the family on the common project of managing the pain. Sometimes they needed to help their child to understand that some somatic sensations were not caused by disease but by tensions such as joy or anxiety. The parents expressed a wish to have professionals with whom they could discuss their perceived shortcomings in caretaking and to guide the child in ways to live with their painful condition.

The pain as a family project

Some families went into a new mode of living during pain episodes. In these families, the question of how to manage and react to the pain was a topic commonly discussed between the parents. Therefore, the pain acted in a way like glue, uniting the husband and wife in solving a common problem. However, Michael Balint[18] wrote, 'A functional illness means that the patient has had a problem that he tried to solve with an illness. The illness enabled him to complain, whereas he was unable to complain about his original problem'. Perhaps the pain may be an unexpressed way for the child to handle family conflicts. Lewandowski et al.[9] reported that families of children with chronic pain generally have poorer family functioning than healthy populations. In our study, some siblings confronted their parents to state that the pain of their brother or sister overwhelmed the family life and drew attention away from their normal activities. Others have found that siblings of children in pain often experienced more emotional or behavioural symptoms than their peers, and that parents did not readily identify these symptoms.[19] One parent in our study reported that their son complained that his sister was pretending to have pain. Therefore, the pain may both unite and divide the family depending on whether other members accept or deny that the child is in pain.

Desire for a specific diagnosis and conversation with a professional

The outcome most wanted by parents after examinations were detection of a somatic disease with a well-defined treatment. No explanation or a vague description of the biopsychosocial model[13] was not satisfying. This model may even give the parents the feeling that they are partly responsible for the condition and give shame that they cannot find a solution. The anxiety that something dangerous may be overlooked and that something must be found that could help the child may make the parents crave further examinations. Smart et al.[20] stated that the mothers needed to be certain they were not missing a physical illness before they could concentrate on a psychological explanation. A vicious cycle of hunting for an understandable explanation may arise, which puts strain on both the child and the parents. Parents reported that they missed having a doctor to whom they could express their difficulties. If doctors were available for consultation at an early stage in the series of pain scenarios, perhaps the conditions could be prevented or aborted. Changing parents' and children's perceptions of the condition expressed as abdominal pain is just the focus of cognitive behavioural therapy. Recently such therapy has been reported to be effective in influencing symptoms and slowly changing behavioural patterns.[21]

Help to interpret and handle the pain

'Butterflies in the stomach are not the same as stomach pain' was the claim by one of the parents. She explained to her child that tension and joy caused this sensation; this feeling is not pain and does not need painkillers. The expression of bodily sensations needs interpretation and guidance from parents mirroring their reactions back to the child.[22] This is a difficult task and depends on the child's age and vocabulary. That a middle ear infection in small children may present itself as stomach pain is an example of the difficulty in interpreting discomfort, especially in small children. Perhaps the parents' own experience of pain is reflected back to the child as a reaction to the child's discomfort. Mothers with chronic pain were five times more likely to report pain in their child than mothers without pain.[23] Sometimes parents' perception of and reaction to the child's pain may be counterproductive in the long term, although in the short term it may facilitate a protective relationship.[24] The reactions described by our parents ranged from ignoring the pain to almost over-involvement. Many parents deviated from their daily routines during pain episodes for instance by making special food or gathering in front of the television. This may constitute a reward. Parents who downplayed the discomfort may be anxious not to aggravate the condition. Another study has shown that some mothers felt a responsibility not to give in to the symptoms of their child because they could be held accountable for sustaining the disability.[20]

Strengths and limitations

The interviewer and first author is herself a GP and child psychiatrist, although she introduced herself as a scientist without responsibility for taking care of the family. She ensured that the family was already taken care of by the health-care system. The informants who took part in our study should be representative of families in Norway. However, we did not recruit many parents with a foreign background. Because we mainly interviewed Norwegians, some precautions are needed in transferring the experiences identified in our study to other populations. Although our informants were recruited from an outpatient hospital setting, the threshold for GPs to refer children with pain to hospital is low, and we believe that the situations described by our parents are relevant for general practice.

CONCLUSION

Children with FGIDS are referred back to their GPs after discharge from hospital without evidence of serious somatic disease. However, the parents and the child are often left without any guidance about how to manage the recurrent pain. Focusing on the pain could drive the family and the doctor into a vicious cycle of hunting for undetected causes instead of focusing on pain management. These families need a competent doctor to discuss handling the pain in daily life and strategies for its management. Cognitive behavioural therapy may be one suggestion for helping patients with FGIDS and their families, although other treatments should also be examined. Further research is needed to help the families of children who receive a diagnosis of FGID.

DECLARATION

Acknowledgement We are grateful to all parents sharing their experiences with us.

Contributors The paper was conceived by AB, KG and PL. AB wrote the first draft, with further contributions from all authors. Questionnaire design, ethics applications and piloting were undertaken by AB. All authors contributed to data interpretation, reviewed successive drafts and approved the final version of the manuscript.

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Competing interests The authors report no conflicts of interests.

Ethics approval The Regional Committees for Medical and Health Research Ethics in Norway approved the study (reference no. 2015/1928). The study has followed the operational principles of the Declaration of Helsinki and has adhere to the Belmont Report principles (respect for persons; beneficence; and justice) when obtaining valid informed consent from parents.

Data sharing statement The data set is not available.

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UNIVERSITAS OSLOENSIS
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Letter to the Editor

Dear Editor of British Medical Journal

We are happy to submit our article to your journal:

Parents' experience when their child has chronic abdominal pain—a qualitative study in Norway

Functional abdominal pain in children is prevalent and bothers the child, their parents, siblings and their GP. Although the biopsychosocial model has now been implemented, we still do not know how to help these children sufficiently. We recognise that British Medical Journal earlier has focused on this topic and consider that our article should be of interest to your readers. The demanding task of helping children with functional abdominal pain concerns GPs frequently according to our experience. We thus hope that you find our article important and will accept it in your journal.

Sincerely yours

Anne Brodwall, on behalf of all authors

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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?	

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Parents' experience when their child has chronic abdominal pain—a qualitative study in Norway

ABSTRACT

Objective Functional abdominal pain occurs frequently in children and adolescents. It is an exclusion diagnosis; somatic diseases have to be ruled out. However little explanation is given for why the child is experiencing pain. The aim was to explore the experiences of parents of children with chronic abdominal pain discharged from hospital without a somatic explanation.

Design The study has a qualitative design. The open questions concerned pain experiences and management. Interviews were conducted at the hospital, at the parents' workplace or in their homes, audiotaped and transcribed. A descriptive content analysis was used to analyze the transcribed text.

Setting Parents to children referred from general practice located in urban and rural areas in two municipals in Norway.

Participants 14 parents of children with functional abdominal pain aged 5–15 years.

Results Fourteen parents participated. Some explained that their child's disability glued the parents together on a common project to help the child. Other parents could tell that siblings got less attention and complained about too much fuss during pain. Parents wished for diagnosis that could be treated efficiently. Some were still anxious that an undetected condition triggered pain. They promoted their doctor to do further examinations. However, some parents knew that social factors could inflict pain, and that sensation like anxiety and "butterfly" tensions need interpretations different from pain. A professional guidance towards the child and parents on how to manage pain was much wanted.

Conclusion A diagnosis of functional abdominal pain should not be the final outcome of a doctors' consultation. Doctors may help these families further by focusing on pain management strategies.

Key words:

Child health, Chronic abdominal pain, Parents, Family, Primary Health Care, Qualitative Research

Strength and limitation

- This study focus on parents to a child with FGIDS just leaving the hospital without any somatic explanation. The experiences in the time-window between hospital examination and support by GPs are expected to be a general setting.
- The problems encountered within families when the focus is on the causes of pain and to a less degree on how to manage and react to pain are highlighted.
- The sample size is small, and only well integrated parents in the society are approached, however we feel that their experience is transferable to many settings in general practice.

INTRODUCTION

In 1958, John Apley [1], a British paediatrician, published his pioneering research in children with abdominal pain, which he labelled recurrent abdominal pain (RAP) syndrome. He found that 10.8% of British schoolchildren had RAP and stated, ‘It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment’. Since then, the term RAP has been replaced by functional gastrointestinal disorders (FGIDS) as defined by the Rome criteria.[1] FGIDS is characterized by chronic or recurrent digestive symptoms without an underlying somatic disease or biochemical abnormality. There are no biological markers of the condition, and the diagnosis is based exclusively on the symptoms reported by the child and parents.[2] The Rome criteria have become an influential standard for defining FGIDS, which is the most common diagnosis among patients with gastrointestinal tract symptoms who consulted gastroenterologists and primary care physicians.

Bonilla and Sapps [3] found that 38% of American schoolchildren and 35% of Columbian children reported weekly abdominal pain. A cross-sectional survey conducted in a school in Sri Lanka identified FGIDS in 28% of the children.[3] The prevalence rates of chronic abdominal pain among school-going children in the United States and Europe range from 0.3–19.0%.[4] In almost 90% of these children, no explanatory organic cause can be identified.[5] A study that reviewed the literature regarding the epidemiology of functional abdominal pain disorders in children found that they were a common problem worldwide.[6]

Chronic pain has a negative impact on the quality of life of children and adolescents, and of their families. Mothers feel restricted in their social life and have problems dealing with the stress of their adolescents’ pain.[7] Chronic illness behaviour also appears to be learned.[8] Families of children with chronic pain generally have poorer family function than healthy populations. Pain-related disability is more consistently connected to family function than to pain intensity.[9] Difficulties in the family may increase the frequency of pain in children, and their pain may in turn affect their parents and family life.[10] Mothers of adolescents with functional abdominal pain were significantly more likely to have a lifetime history of irritable bowel syndrome, migraine, anxiety, depressive or somatoform disorders compared with other mothers.[11]

The treatment of paediatric abdominal pain should attempt to focus on the influence of the parents.[12] Parental responses to pain may be an important target for helping adolescents with their chronic pain.[13] Exclusion of organic disorders is important for making the diagnosis of FGIDS [14] after which it must be explained to the parents and the child that further examination will not change the diagnosis or the available treatment. However, this situation may trigger suspicion in parents and a feeling that the medical establishment has failed. In many parts of Norway and probably in other countries the exclusion of somatic causes terminates the examination and follow-up by the specialist services and further support are expected to be given by the GP. There is not always a multidisciplinary level of care between the GP and the specialist services.

This study examines different experiences told by parents in handling recurrent abdominal pain in one of their children. We want to know more, not only about mother-child or child-parents relation to the pain, but also the siblings' reactions to the problem.

The aim of our study was to explore the experiences of parents of children and adolescents with chronic abdominal pain who were discharged from hospital without a somatic explanation.

METHODS

A qualitative design with individual interviews was chosen. One aim is to condense single statements of experience into overarching concepts by text analysis of transcripts. By comparing comprehension by each researcher a common agreed understanding may be achieved.[15] A semi-structured interview guide was developed (Table 1) comprising 10 open-ended questions and additional follow-up questions that allowed the interviewer to probe more deeply.[16] The questions were developed after discussions and agreement within the interdisciplinary research team who all had experience with children and adolescent patients. Two medical students commented on the questions. After two interviews, the guide was evaluated and some small modifications were made.

Table 1. Interview guide

1. Could you tell about the last time your child had stomach pain?

2. How does your child react when he/she has stomach pain?

3. How do your spouse and the other children react when your child has stomach pain?

4. How do you experience the situation at home when your child has stomach pain?

5. Do you have some thoughts about the reason for your child's stomach pain?

6. What are you doing when your child has stomach pain?

7. How do you explain to your child about the stomach pain?

8. What did you experience last time you visited the hospital with your child?

9. You have told me they did not find anything physically wrong with your child at the hospital. How did you feel about that?

10. Could you please explain your feelings about the follow-up at the hospital when all tests were normal?

11. Which country do you and your family come from?

12. What is the tradition in the country you come from in managing pain? Any differences from Norway?

13. What could make you feel more secure about your child's stomach pain?

14. Is there anything more you would like to add concerning your child's stomach pain?

15. How did you experience this interview?

Recruitment

We recruited participants referred to a hospital located in a middle-sized Norwegian town that covers 440,000 inhabitants within the town and surrounding area. Inclusion criteria: Children/adolescents 5-15 years old with abdominal pain, referred to hospital from a GP who had not found a diagnosis to the pain. Exclusion criteria: Not able to communicate in Norwegian. A dedicated nurse at the outpatient department recruited parents to children aged 5-15 years old recently examined for recurrent abdominal pain.

She informed the parents about the study, handed out written information and obtained the phone number from those who wished to participate. The first author contacted the parents to arrange an interview. When fourteen interviews were completed, saturation was achieved. We did not identify new information by adding more participants. The recruitment therefore was stopped.[17]

Interviews

The first author, who is a female GP and child- and adolescent psychiatrist, interviewed the parents. The parents knew that the interviewer was a physician; in the interview setting, however, she presented herself as a researcher with no therapeutic responsibility. The interviews were held in localities that suited the parents: one in the family’s home, one at the parent’s work place, the other interviews at the author’s office at the hospital. Different locations were approved to make it easier for these busy parents. All interviews were in a quite room with no disturbances. One interview was conducted by telephone. The interviews lasted 45–75 minutes.

Data analysis

The interviews were audiotape recorded and transcribed by the first author. Qualitative content analysis was conducted based on Graneheim and Lundman.[16]

All three authors read the transcripts individually while listening to the audiotape (ensuring a correct transcription) and worked together on their interpretation to achieve a common understanding and to reinforce the level of trust and credibility.[16]

We read the transcripts several times. The texts were sorted into meaning units, shortened and coded. Then the codes were categorized into sub-categories and categories. From the categories main themes emerged.

RESULTS

Information about the interviewees

In total 10 of the interview subjects were Norwegian. Four foreign parents had lived in Norway for several years and mastered the language well. All, except for two parents, lived together. The children with abdominal pain were 6–13 years old. Five fathers and 10 mothers were interviewed, both parents interviewed together in one family. In 13 families the child had siblings, nine children had one sibling, two children had two siblings and two children had four siblings.

The main themes

We identified three main themes: 1) how the pain rules the family, 2) the desire for a specific diagnosis and discussion with a professional, 3) interpreting and handling the child's pain.

How the pain rules the family

Some parents reported that their child's pain affected the total family. The strength and duration of the pain seemed to be factors that partly decided the degree to which the family life was changed. Major changes in their lives could result, such as deciding to stay out of work and/or not prioritizing their social life: '*The whole family goes into another mode. We are around him and must adapt all our activities to him. We are thinking of this daily, every hour. It is the main subject of conversation between my wife and me*'. Other families had to make some small adjustments to their everyday life. In some families, there was no significant change even if the child had pain; their life went on more or less the same: '*He decides if he wants to eat or not, but I don't think it affects us much*'. The reactions among the siblings, reported by the parents, ranged from calling the affected child a drama queen to not noticing the pain at all: '*The brother can be irritated sometimes, he thinks there is a lot of fuss about* *this (pain) and suspects that sometimes she is pretending*'. Some of the parents in our study recognized the symptoms and the child's situation because they had experienced the same stomach pain themselves. Most parents were worried about their child's situation and that it affected all family members much: '*I show a great deal of care, but it is very difficult. I get irritated sometimes but cannot show it. We hear complaints from him every day and it is so exhausting*'.

Desire for a specific diagnosis and desire for discussion with a professional

All parents considered that a physical condition caused their children's stomach-aches. However, some parents were aware that stress at school or difficulties with friends impacted the child, perhaps triggering or causing pain: '*Our opinion is that it could be several factors, it gets worse during periods with school- or other social problems*' . The parents reported frustration after their visits to hospital because they received no suggestions of ways to help the child. Parents expressed this annoyance differently: '*The doctors were good at informing us that these symptoms are not dangerous, but we know no more about the reasons for the pain. That is frustrating, but we must learn to live with it*'.

The goal for most parents was to receive a medical diagnosis leading to a treatment that would make their child pain free. Because this goal was not met, their child's pain continued to rule their daily life.

Since there were no external causes to the child's aches, the parents felt that something was wrong with their parenting. They were then in charge for helping their child without knowing what to do.

They felt to be blamed, which was experienced very hurting: '*Yes, I am dictating to the doctors, telling them what kind of medicine he should have and that we want to come back to the hospital. I must take the responsibility for getting medical help*'. '*It is difficult and we despair because we do not know what we can do. If there had been a diagnosis, maybe it would have led to a treatment that would have helped. It is extremely sad and frustrating*'**.** The pain was an important topic in the conversations between the parents. They reported a wish to have a professional person for both the child and the parents to consult: '*It should be possible for parents who have children with chronic illnesses and no certain diagnosis to have a person to communicate with*' and '*The only thing they could help him with is that he would* *have someone to talk to, so that he would not keep everything inside himself* '. Some parents wanted a quick fix or a healing tablet. They wanted their child to have further medical examinations, and that this should happen quickly: '*They could have examined more, because what if this is something very serious'?* Some parents also hoped that a medicine would soon become available that could fix the symptoms: '*We hope that there will soon be a quick fix, a medicine that will solve the problem*'.

Interpreting and handling the child's pain

Parents often tried to teach their child what pain really is: '*Butterflies in the stomach is not the same as stomach pain, but she has a tendency to call everything stomach pain*'. When the child had days with severe pain, the parents dealt with the situation in different ways: '*She must go to the toilet; she is not getting any painkillers and she must learn to avoid the food she is reacting to'*. The parents reported that the sisters and brothers also showed different reactions. '*We all do not have so much to do with it. It is not so bad that we need to adapt our lives to this, but she must just learn to live with it*'. Some parents were afraid to be viewed as 'hysterical mothers'. They said that they understood that these thoughts and feelings were something they produced themselves, but they still feared not being taken seriously by the doctors. One parent reported that the child did not want to talk about the pain: '*He looks away, listens to YouTube, and he will not communicate with us. He puts on earplugs and lets the time flow away*'. Some families gathered to watch films or television together when the child had stomach pain because they felt that it drew the focus away from the pain: '*We skip sport or exercise that day, instead we relax at home together. We ask her what she wants to do, try to calm her down, watch a film together, play cards and try to distract her from the pain*'.

DISCUSSION

Parents of children with recurrent abdominal pain recently discharged from hospital without an identified somatic cause, felt frustrated because they did not receive specific help. They wanted a somatic explanation and a treatment that could solve the problem and alleviate their responsibility for a child in pain.

They often reported that in a way, the child's condition focused the whole family in managing the pain. Sometimes they needed to help their child to understand that some somatic sensations were not caused by disease but by tensions such as joy or anxiety. The parents expressed a wish to have professionals with whom they could discuss their perceived shortcomings in caretaking and to guide the child in ways to live with their painful condition.

How the pain rules the family

Some families went into a new mode of living during pain episodes. In these families, the question of how to manage and react to the pain was a topic commonly discussed between the parents. Therefore, the pain acted in a way like glue, uniting the husband and wife in solving a common problem. However, Michael Balint[18] wrote, 'A functional illness means that the patient has had a problem that he tried to solve with an illness. The illness enabled him to complain, whereas he was unable to complain about his original problem'. Perhaps the pain may be an unexpressed way for the child to handle family conflicts. Lewandowski et al.[9] reported that families of children with chronic pain generally have poorer family functioning than healthy populations. In our study, some siblings confronted their parents to state that the pain of their brother or sister overwhelmed the family life and drew attention away from their normal activities. Others have found that siblings of children in pain often experienced more emotional or behavioural symptoms than their peers, and that parents did not readily identify these symptoms.[19] One parent in our study reported that their son complained that his sister was pretending to have pain. Therefore, the pain may both unite and divide the family depending on whether other members accept or deny that the child is in pain.

Desire for a specific diagnosis and conversation with a professional

The outcome most wanted by parents after examinations were detection of a somatic disease with a well-defined treatment. No explanation or a vague description of the biopsychosocial model[13] was not satisfying. This model may even give the parents the feeling that they are partly responsible for the condition and give shame that they cannot find a solution. The anxiety that something dangerous may be overlooked and that something must be found that could help the child may make the parents crave further examinations. Smart et al.[20] stated that the mothers needed to be certain they were not missing a physical illness before they could concentrate on a psychological explanation. A vicious cycle of hunting for an understandable explanation may arise, which puts strain on both the child and the parents. Parents reported that they missed having a doctor to whom they could express their difficulties. If doctors were available for consultation at an early stage in the series of pain scenarios, perhaps the conditions could be prevented or aborted. Changing parents' and children's perceptions of the condition expressed as abdominal pain is just the focus of cognitive behavioural therapy. Recently such therapy has been reported to be effective in influencing symptoms and slowly changing behavioural patterns.[21] To change parent's responses to this pain even a brief phone-call applying Social learning and cognitive behavioural therapy instead of a in person contact could be effective. [22]

'Butterflies in the stomach are not the same as stomach pain' was the claim by one of the parents. She explained to her child that tension and joy caused this sensation; this feeling is not pain and does not need painkillers. The expression of bodily sensations needs interpretation and guidance from parents mirroring their reactions back to the child.[23] This is a difficult task and depends on the child's age and vocabulary. That a middle ear infection in small children may present itself as stomach pain is an example of the difficulty in interpreting discomfort, especially in small children. Perhaps the parents' own experience of pain is reflected back to the child as a reaction to the child's discomfort. Mothers with chronic pain were five times more likely to report pain in their child than mothers without pain.[24] Sometimes parents' perception of and reaction to the child's pain may be counterproductive in the long term, although in the short term it may facilitate a protective relationship.[25] The reactions described by our parents ranged from ignoring the pain to almost over-involvement. Many parents deviated from their daily routines during pain episodes for instance by making special food or gathering in front of the television. This may constitute a reward. Parents who downplayed the discomfort may be anxious not to aggravate the condition. Another study has shown that some mothers felt a responsibility not to give in to the symptoms of their child because they could be held accountable for sustaining the disability.[20]

Strengths and limitations

The interviewer and first author is herself a GP and child psychiatrist, although she introduced herself as a scientist without responsibility for taking care of the family. She ensured that the family was already taken care of by the health-care system. Full privacy was ensured although the interviews were conducted in different settings. The informants who took part in our study should be representative of families in Norway. However, we did not recruit many parents with a foreign background. Because we mainly interviewed Norwegians, some precautions are needed in transferring the experiences identified in our study to other populations. Although our informants were recruited from an outpatient hospital setting, the threshold for GPs to refer children with pain to hospital is low, and we believe that the situations described by our parents are relevant for general practice.

CONCLUSION

Children with FGIDS are referred back to their GPs after discharge from hospital without evidence of serious somatic disease. However, the parents and the child may be left without any guidance about how to manage the recurrent pain. Focusing on the pain could drive the family and the doctor into a vicious cycle of hunting for undetected causes instead of focusing on pain management. Functional pain is a challenging subject. These families need a caring physician with time and interest for discussing and excluding other diagnosis. Psycho-education about the pain and strategies in how to handle the pain in daily life also is an important part of the treatment. Cognitive behavioural therapy may be one suggestion for helping patients with FGIDS and their families, although other treatments should also be examined. Further research is needed to help the families of children who receive a diagnosis of FGIDS.

DECLARATION

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Contributors The paper was conceived by AB, KG and PL. AB wrote the first draft, with further contributions from all authors. Questionnaire design, ethics applications and piloting were undertaken by AB. All authors contributed to data interpretation, reviewed successive drafts and approved the final version of the manuscript.

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Competing interests The authors report no conflicts of interests.

Ethics approval The Regional Committees for Medical and Health Research Ethics in Norway approved the study (reference no. 2015/1928). The study has followed the operational principles of the Declaration of Helsinki and has adhere to the Belmont Report principles (respect for persons; beneficence; and justice) when obtaining valid informed consent from parents.

Patient and Public Involvement statement There were no interactions with parents in developing the interview guide. The participants were informed that the results were to be published in an article. When the article is ready the informants will be informed by phone.

Data sharing statement The data set is not available.

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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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Parents' experience when their child has chronic abdominal pain—a qualitative study in Norway

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ABSTRACT

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Conclusion A diagnosis of functional abdominal pain should not be the final outcome of a doctors' consultation. Doctors may help these families further by focusing on pain management strategies.

Key words:

Child health, Chronic abdominal pain, Parents, Family, Primary Health Care, Qualitative Research

Strength and limitation

- The individual interviews reveals that the whole family is affected when one child has chronic abdominal pain.
- The time of the interviews with parents of children were when the child had just been discharged from hospital, this enabled experiences which had not faded.
- The sample size is small, and only well integrated parents in the society are approached, however we feel that their experience is transferable to many settings in general practice.

INTRODUCTION

In 1958, John Apley [1], a British paediatrician, published his pioneering research in children with abdominal pain, which he labelled recurrent abdominal pain (RAP) syndrome. He found that 10.8% of British schoolchildren had RAP and stated, 'It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment'. Since then, the term RAP has been replaced by functional gastrointestinal disorders (FGIDS) as defined by the Rome criteria.[1] FGIDS is characterized by chronic or recurrent digestive symptoms without an underlying somatic disease or biochemical abnormality. There are no biological markers of the condition, and the diagnosis is based exclusively on the symptoms reported by the child and parents.[2] The Rome criteria have become an influential standard for defining FGIDS, which is the most common diagnosis among patients with gastrointestinal tract symptoms who consulted gastroenterologists and primary care physicians.

Bonilla and Sapps [3] found that 38% of American schoolchildren and 35% of Columbian children reported weekly abdominal pain. A cross-sectional survey conducted in a school in Sri Lanka identified FGIDS in 28% of the children.[3] The prevalence rates of chronic abdominal pain among school-going children in the United States and Europe range from 0.3–19.0%.[4] In almost 90% of these children, no explanatory organic cause can be identified.[5] A study that reviewed the literature regarding the epidemiology of functional abdominal pain disorders in children found that they were a common problem worldwide.[6]

Chronic pain has a negative impact on the quality of life of children and adolescents, and of their families. Mothers feel restricted in their social life and have problems dealing with the stress of their adolescents' pain.[7] Chronic illness behaviour also appears to be learned.[8] Families of children with chronic pain generally have poorer family function than healthy populations. Pain-related disability is more consistently connected to family function than to pain intensity.[9] Difficulties in the family may increase the frequency of pain in children, and their pain may in turn affect their parents and family life.[10] Mothers of adolescents with functional abdominal pain were significantly more likely to have a lifetime history of irritable bowel syndrome, migraine, anxiety, depressive or somatoform disorders compared with other mothers.[11]

The treatment of paediatric abdominal pain should attempt to focus on the influence of the parents.[12] Parental responses to pain may be an important target for helping adolescents with their chronic pain.[13] Exclusion of organic disorders is important for making the diagnosis of FGIDS [14] after which it must be explained to the parents and the child/adolescent that further examination will not change the diagnosis or the available treatment. However, this situation may trigger suspicion in parents and a feeling that the medical establishment has failed. In many parts of Norway and probably in other countries the exclusion of somatic causes terminates the examination and follow-up by the specialist services and further support are expected to be given by the GP. Often the GP is without any support by specially trained healthcare personal like psychologist or nurses in these cases. This study examines different experiences reported by parents in handling recurrent abdominal pain in one of their children. We want to know more, not only about mother-child or child-parents relation to the pain, but also the siblings' reactions to the problem.

The aim of our study was to explore the experiences of parents of children and adolescents with chronic abdominal pain who were discharged from hospital without a somatic explanation.

METHODS

A qualitative design with individual interviews was chosen. One aim was to condense single statements of experience into overarching concepts by text analysis of transcripts. By comparing comprehension by each researcher a common agreed understanding may be achieved.[15] A semi-structured interview guide was developed (Table 1) comprising 10 open-ended questions and additional follow-up questions that allowed the interviewer to probe more deeply.[16] The questions were developed after discussions and agreements within the interdisciplinary research team who all had experience with children and adolescent patients. After two interviews, the guide was evaluated and some small modifications were made.

Patient and Public Involvement statement There were no interactions with parents in developing the interview guide. The participants were informed that the results were to be published in an article. When the article is ready the informants will be informed by phone.

Table 1. Interview guide

1. Could you tell about the last time your child had stomach pain?

2. How does your child react when he/she has stomach pain?

3. How do your spouse and the other children react when your child has stomach pain?

4. How do you experience the situation at home when your child has stomach pain?

5. Do you have some thoughts about the reason for your child's stomach pain?

6. What are you doing when your child has stomach pain?

7. How do you explain to your child about the stomach pain?

8. What did you experience last time you visited the hospital with your child?

9. You have told me they did not find anything physically wrong with your child at the hospital. How did you feel about that?

10. Could you please explain your feelings about the follow-up at the hospital when all tests were normal?

11. Which country do you and your family come from?

12. What is the tradition in the country you come from in managing pain? Any differences from Norway?

13. What could make you feel more secure about your child's stomach pain?

14. Is there anything more you would like to add concerning your child's stomach pain?

15. How did you experience this interview?

Recruitment

We recruited participants referred to a hospital located in a middle-sized Norwegian town that covers 440,000 inhabitants within the town and surrounding area. Inclusion criteria: Children/adolescents 5-15 years old with abdominal pain, referred to hospital from a GP who had not found a diagnosis to the pain. Exclusion criteria: Not able to communicate in Norwegian. A dedicated nurse at the outpatient department recruited parents of children aged 5-15 years old recently presenting with recurrent abdominal pain.

She informed the parents about the study, handed out written information and obtained the phone number from those who wished to participate. The first author contacted the parents to arrange an interview. Fourteen parents were interviewed, saturation was then achieved. We did not identify new information by adding more participants. The recruitment therefore was stopped.[17]

Interviews

The first author, who is a female GP and child- and adolescent psychiatrist, interviewed the parents. The parents knew that the interviewer was a physician; in the interview setting, however, she presented herself as a researcher with no therapeutic responsibility**.** The interviews were held in localities that suited the parents: one in the family's home, one at the parent's work place, the other interviews at the author's office at the hospital. Different locations were approved to make it easier for these busy parents. All interviews were in a room with no disturbances. . One interview was conducted by telephone. The interviews lasted 45–75 minutes.

Data analysis

The interviews were audiotape recorded and transcribed by the first author. Qualitative content analysis was conducted based on Graneheim and Lundman.[16] All three authors read the transcripts individually while listening to the audiotape (ensuring a correct transcription) and worked together on their interpretation to achieve a common understanding and to reinforce the level of trust and credibility.[16] We read the transcripts several times. The texts were sorted into meaning units, shortened and coded. Then the codes were categorized into sub-categories and categories. From the categories main themes emerged.

RESULTS

Information about the interviewees

In total 10 of the interview subjects were Norwegian. Four foreign parents had lived in Norway for several years and mastered the language well. All, except for two parents, lived together. The children with abdominal pain were 6–13 years old. Five fathers and 10 mothers were interviewed, both parents interviewed together in one family. In 13 families the child had siblings, nine children had one sibling, two children had two siblings and two children had four siblings.

The main themes

We identified three main themes: 1) how the pain rules the family**,** 2) the desire for a specific diagnosis and discussion with a professional, 3) interpreting and handling the child's pain.

How the pain rules the family

Some parents reported that their child's pain affected the total family. The strength and duration of the pain seemed to be factors that partly decided the degree to which the family life was changed. Major changes in their lives could result, such as deciding to stay out of work and/or not prioritizing their social life: '*The whole family goes into another mode. We are around him and must adapt all our activities to him. We are thinking of this daily, every hour. It is the main subject of conversation between my wife and me*'. Other families had to make some small adjustments to their everyday life. In some families, there was no significant change even if the child had pain; their life went on more or less the same: '*He decides if he wants to eat or not, but I don't think it affects us much*' The reactions among the siblings, reported by the parents, ranged from calling the affected child a drama queen to not noticing the pain at all: '*The brother can be irritated sometimes, he thinks there is a lot of fuss about this (pain) and suspects that sometimes she is pretending*' Some of the parents in our study recognized the symptoms and the child's situation because they had experienced the same stomach pain themselves. Most parents were worried about their child's situation and that it affected all family members much: '*I show a great deal of care, but it is very difficult. I get irritated sometimes but cannot show it. We hear complaints from him every day and it is so exhausting*'.

Desire for a specific diagnosis and desire for discussion with a professional

All parents considered that a physical condition caused their children's stomach-aches. However, some parents were aware that stress at school or difficulties with friends impacted the child, perhaps triggering or causing pain: '*Our opinion is that it could be several factors, it gets worse during periods with school- or other social problems*' The parents reported frustration after their visits to hospital because they received no suggestions of ways to help the child. Parents expressed this annoyance differently: '*The doctors were good at informing us that these symptoms are not dangerous, but we know no more about the reasons for the pain. That is frustrating, but we must learn to live with it*'.

The goal for most parents was to receive a medical diagnosis leading to a treatment that would make their child pain free. Because this goal was not met, their child's pain continued to rule their daily life. Since there were no external causes to the child's aches, the parents felt that something was wrong with their parenting. They were then in charge for helping their child without knowing what to do.

They felt to be blamed, which was experienced very hurting: '*Yes, I am dictating the doctors, telling them what kind of medicine he should have and that we want to come back to the hospital. I must take the responsibility for getting medical help*' and '*It is difficult and we despair because we do not know what we can do. If there had been a diagnosis, maybe it would have led to a treatment that would have helped. It is extremely sad and frustrating*'. The pain was an important topic in the conversations between the parents. They reported a wish to have a professional person for both the child and the parents to consult: '*It should be possible for parents who have children with chronic illnesses and no certain diagnosis to have a person to communicate with*' '*The only thing they could help him with is that he would have someone to talk to, so that he would not keep everything inside himself* '.Some parents wanted a quick fix or a healing tablet. They wanted their child to have further medical examinations, and that this should happen quickly: '*They could have examined more, because what if this is something very serious'?* Some parents also hoped that a medicine would soon become available that could remove the symptoms: '*We hope that there will soon be a quick fix, a medicine that will solve the problem*'.

Interpreting and handling the child's pain

Parents often tried to teach their child to distinguish pain from other sensations: 'A sensation of *butterflies is not the same as stomach pain, but she has a tendency to call everything stomach pain*'. When the child had days with severe pain, the parents dealt with the situation in different ways: '*She must go to the toilet; she is not getting any painkillers and she must learn to avoid the food she is reacting to'*. The parents reported that the sisters and brothers also showed different reactions: 'We usually do not get involved**-**. *It is not so bad that we need to adapt our lives to this, but she must just learn to live with it*'. Some parents were afraid to be viewed as 'hysterical mothers'. They said that they understood that these thoughts and feelings were something they produced themselves, but they still feared not being taken seriously by the doctors. One parent reported that the child did not want to talk about the pain: '*He looks away, listens to YouTube, and he will not communicate with us. He puts on earplugs and lets the time flow away*'. Some families gathered to watch films or television together when the child had stomach pain because they felt that it reduced the attention to the pain: '*We skip sport or exercise that day, instead we relax at home together. We ask her what she wants to do, try to calm her down, watch a film together, play cards and try to distract her from the pain*'.

DISCUSSION

Parents of children with recurrent abdominal pain recently discharged from hospital without an identified somatic cause, felt frustrated because they did not receive specific help. They wanted a somatic explanation and a treatment that could solve the problem and alleviate their responsibility for a child in pain. They often reported that in a way, the child's condition focused the whole family in managing the pain. Sometimes they needed to help their child to understand that some somatic sensations were not caused by disease but by tensions such as joy or anxiety. The parents expressed a wish to have professionals with whom they could discuss their perceived shortcomings in caretaking and to guide the child in ways to live with their painful condition.

How the pain rules the family

Some families went into a new mode of living during pain episodes. In these families, the question of how to manage and react to the pain was a topic commonly discussed between the parents. Therefore, the pain acted in a way like glue, uniting the husband and wife in solving a common problem. However, Michael Balint[18] wrote, ‘A functional illness means that the patient has had a problem that he tried to solve with an illness. The illness enabled him to complain, whereas he was unable to complain about his original problem’. Perhaps the pain may be an unexpressed way for the child to handle family conflicts. Lewandowski et al.[9] reported that families of children with chronic pain generally have poorer family functioning than healthy populations. In our study, some siblings confronted their parents to state that the pain of their brother or sister overwhelmed the family life and drew attention away from their normal activities. Others have found that siblings of children in pain often experienced more emotional or behavioural symptoms than their peers, and that parents did not readily identify these symptoms.[19] One parent in our study reported that their son complained that his sister was pretending to have pain. Therefore, the pain may both unite and divide the family depending on whether other members accept or deny that the child is in pain.

Desire for a specific diagnosis and conversation with a professional

The outcome most wanted by parents after examinations were detection of a somatic disease with a well-defined treatment. No explanation or a vague description of the biopsychosocial model[13] was not satisfying. This model may even give the parents the feeling that they are partly responsible for the condition and give shame that they cannot find a solution. The anxiety that something dangerous may be overlooked may make the parents crave further examinations. Smart et al.[20] stated that the mothers needed to be certain they were not missing a physical illness before they could concentrate on a psychological explanation. A vicious cycle of hunting for an understandable explanation may arise, which puts strain on both the child and the parents.

Parents reported that they missed having a doctor to whom they could express their difficulties. If doctors were available for consultation at an early stage in the series of pain scenarios, perhaps the conditions could be prevented or aborted. Changing parents’ and children’s perceptions of the condition, expressed as abdominal pain, is just the focus of cognitive behavioural therapy. Recently such therapy has been reported to be effective in influencing symptoms and slowly changing behavioural patterns.[21] To change the parent's responses to this pain even a brief phone-call applying social learning and cognitive behavioural therapy instead of an impersonal contact could be effective. [22]

'A sensation of butterflies in the stomach are not the same as stomach pain' was the claim by one of the parents. She explained to her child that tension and joy caused this sensation; this feeling is not pain and does not need painkillers. The expression of bodily sensations needs interpretation and guidance from parents mirroring their reactions back to the child.[23] This is a difficult task and depends on the child's age and vocabulary. That a middle ear infection in small children may present itself as stomach pain is an example of the difficulty in interpreting discomfort, especially in small children. Perhaps the parents' own experience of pain is reflected back to the child as a reaction to the child's discomfort. Mothers with chronic pain were five times more likely to report pain in their child than mothers without pain.[24] Sometimes parents' perception of and reaction to the child's pain may be counterproductive in the long term, although in the short term it may facilitate a protective relationship.[25] The reactions described by our parents ranged from ignoring the pain to almost over-involvement. Many parents deviated from their daily routines during pain episodes for instance by making special food or gathering in front of the television. This may constitute a reward. Parents who downplayed the discomfort may be anxious not to aggravate the condition. Another study has shown that some mothers felt a responsibility not to give in to the symptoms of their child because they could be held accountable for sustaining the disability.[20]

Strengths and limitations

The interviewer and first author is herself a GP and child psychiatrist, although she introduced herself as a scientist without responsibility for taking care of the family. She ensured that the family was already taken care of by the health-care system. Full privacy was ensured although the interviews were conducted in different settings. The informants who took part in our study should be representative of families in Norway. However, we did not recruit many parents with a foreign background. Because we mainly interviewed Norwegians, some precautions are needed in transferring the experiences identified in our study to other populations. Although our informants were recruited from an outpatient hospital setting, the threshold for GPs to refer children with pain to hospital is low, and we believe that the situations described by our parents are relevant for general practice.

CONCLUSION

Children with FGIDS are referred back to their GPs after discharge from hospital without evidence of serious somatic disease. However, the parents and the child may be left without any guidance about how to manage the recurrent pain. Focusing on the pain could drive the family and the doctor into a vicious cycle of hunting for undetected causes instead of focusing on pain management. Functional pain is a challenging subject. These families need a caring physician with time and interest for discussing and excluding other diagnosis. Psycho-education about the pain and strategies in how to handle the pain in daily life also is an important part of the treatment. Cognitive behavioural therapy may be one suggestion for helping patients with FGIDS and their families, although other treatments should also be examined. Further research is needed to help the families of children who receive a diagnosis of FGID.

DECLARATION

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Contributors The paper was conceived by AB, KG and PL. AB wrote the first draft, with further contributions from all authors. Questionnaire design, ethics applications and piloting were undertaken by AB. All authors contributed to data interpretation, reviewed successive drafts and approved the final version of the manuscript.

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Competing interests The authors report no conflicts of interests.

Ethics approval The Regional Committees for Medical and Health Research Ethics in Norway approved the study (reference no. 2015/1928). The study has followed the operational principles of the Declaration of Helsinki and has adhere to the Belmont Report principles (respect for persons; beneficence; and justice) when obtaining valid informed consent from parents.

Data sharing statement The data set is not available.

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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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