Children and adolescents with functional gastrointestinal disorders

Children’s, adolescents’, parents’ and general practitioners’ experiences with functional gastrointestinal disorders

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Contents

1. Abbreviations

DSM: The Diagnostic and Statistical Manual of Mental Disorders

FGIDs: functional gastrointestinal disorders

GI: gastrointestinal

GP: general practitioner

IBS: irritable bowel syndrome

ICD: International Statistical Classification of Diseases and Related Health Problems

RAP: recurrent abdominal pain

VVHF: Vestre Viken Health Trust

WHO: World Health Organization

2. Preface

2.1 Motivation

I started out with my interest in children's and adolescents' somatic and mental health. The zone where the somatic symptoms could be a signal of not just physical symptoms but of psychological stress as well especially interested me. The work started with a desire to understand more about these symptoms. I began to notice children and adolescents who came to me as their GP with different types of pain. Children down to five years old told me about pain in muscles, head and abdomen. Their parents often worried that the children's symptoms should be underlying serious disease. They therefore wanted their child to have different types of investigations to be quite sure the pain was not dangerous. I wondered what the parents' worries did to their children and adolescents and also if and how the parents' lives were affected by the children's and adolescents' symptoms. As I write in "Personal experiences," abdominal symptoms such as pain were the symptoms the children and adolescents often presented to me. I reflected on the fact that this was a patient group that I met quite often as a GP. This was my motivation, to try to understand more about children and adolescents with abdominal symptoms and their families.

2.2 Co-authors

Study I: Per Lagerløv
Kari Glavin

Studies II–IV: Mette Brekke

2.3 Acknowledgments

The research and the doctoral thesis were carried out without any formal connection to a university.

I am grateful to the Child and Adolescent Department, Drammen hospital for giving me the possibility to recruit parents to children and adolescents with FGIDs to the study.

I want to thank Reidun Kjemprud, (the nurse in the outdoor clinic), for her enormous help with the recruitment of parents of children and adolescents with FGIDs. Without your assistance there would have been no interviews and no study.

The participants in Studies I, II and III, the parents of the children and adolescents and later the children and adolescents themselves, made it possible to turn my thoughts and wonders into a concrete study. I am especially thankful for their openness and goodwill in sharing their stories, worries and difficult situations. Without the GPs in Study IV, the thesis would not have been completed. Through my experience as a GP, I know how busy their days are. I am therefore impressed and thankful that they devoted time to share their thoughts and views about the patients with FGIDs.

Professor Per Lagerløv, my co-author on the first article, with his enormous knowledge and experience as a clinician as well as researcher, has inspired me and supported me from the start of the study. Professor Kari Glavin, also my co-author on the first article, has shared her great experience in qualitative research, a topic that was new to me in 2016. I am deeply grateful for their genuine involvement and cooperation with quick responses and constructive engagement. If the start of the study had not been that positive, I would never have continued with the study. They inspired me to continue my work.

I would also like to express my sincere gratitude to Professor Mette Brekke, the co-author on articles II, III and IV. You have introduced me to the art of academic writing and encouraged me to continue my exploration within the topic of children and adolescents with FGIDs. Your support has been tremendous. You have always rapidly answered my questions with great insights and thorough comments, even in late evenings and weekends. The cooperation with such an experienced and skilled colleague as you has truly been a great inspiration and of huge importance for the completion of my study.

Finally, I would like to thank my wonderful family for being patient with me and for supporting me. The research has been conducted in addition to my work at the hospital, therefore evenings and holidays have been occupied with writing. I hope the excitement the

work has brought for me can inspire you in pursuing your interests. Thank you for listening to me, inspiring discussions and for letting me finish this work.

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Anne Brodwall

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Studies I, II: The Norwegian Committee on Research in General Practice (Allmennmedisinsk forskningsutvalg – AFU)
Studies III–IV: None

3. Norwegian summary/Norsk sammendrag

Bakgrunn:

Barn og ungdom med funksjonelle gastrointestinale lidelser samt familiene deres påvirkes ofte betydelig av smertetilstanden i hverdagen. Som regel blir barna utredet og fulgt opp hos fastlegen, selv om mange også er innom annenlinjetjenesten. Mine erfaringer som fastlege og senere som barne-og ungdomspsykiater med bl.a. arbeid på barneavdeling gjorde at jeg ble ekstra oppmerksom på disse pasienten og deres familier. Ikke minst ble jeg overrasket over det relativt stort antall henvisninger til spesialisthelsetjenesten for vurdering og eventuell behandling av abdominalsmertene. Ca. 600 barn og unge med funksjonelle gastrointestinale lidelser ble henvist fra fastlegene til Barne-og ungdomsavdelingen ved Drammen sykehus i 2014

Formål:

Målet for denne avhandlingen var å utforske mer om disse barna og ungdommenes, deres familiers og også fastlegenes erfaring med og refleksjoner rundt funksjonelle gastrointestinale lidelser. Fokus var på hva de tenkte kunne være årsak til symptomene og hva som kunne hjelpe dem i denne smertesituasjonen.

Materiale og metode:

Barna og ungdommene hadde blitt henvist til Barne-og ungdomsavdelingen, Drammen sykehus, Vestre Viken Helseforetak (VVHF) i 2014 og 2015. De var da 6-13 år gamle. I 2016 ble det gjort en intervjustudie med foreldrene deres der fokus var på foreldrenes/familienes erfaringer med å ha barn/ungdommer med funksjonelle gastrointestinale lidelser.

I 2019 ble det gjort en «follow-up» studie med de samme foreldrene for å se hvordan familienes, barnas og ungdommenes situasjon var tre år etter første studie.

I 2020 ble det gjort en intervjustudie med barna/ungdommene selv. De hadde da blitt 11-18 år gamle.

Senere i 2020 ble det gjort en intervjuundersøkelse av fastleger i nedslagsfeltet til Barne-og ungdomsavdelingen ved Drammen sykehus om deres erfaringer med barne-og ungdomspasienter som hadde funksjonelle gastrointestinale lidelser.

Det ble brukt kvalitativ metode med semistrukturerte individualintervjuer i de fire studiene. Etter å ha vurdert flere analysemetoder ble kvalitativt innholds analyse metode etter Graneheim og Lundman valgt. Metoden systematiserer innholdselementer som er relevante for å utdype og fortolke spesifikke problemstillinger. Jeg gjennomførte alle intervju og transkripsjoner. Begge forfatterne (alle tre i studie 1) leste gjennom transkripsjonene flere ganger. Ved uenigheter diskuterte man seg frem til løsninger som var akseptable for alle.

Resultater:

Foreldrene var både i 2016 og 2019 opptatt av å få mer informasjon om tilstanden og at barnet /ungdommen deres skulle å få en diagnose samt en effektiv behandling. De mente at symptomene hovedsakelig hadde en fysisk årsak. Noen tenkte imidlertid at vansker på skolen eller med venner kunne virke inn på barnet/ungdommen.

Av opprinnelig 14 (syv gutter og syv jenter) barn/ungdom i 2016, hadde åtte (fire gutter og fire jenter) ikke lenger funksjonelle gastrointestinale lidelser i 2019. Flere av barna/ungdommene hadde hatt flere uker og måneders skolefravær samt uteblivelse fra samvær med venner og fra fritidsaktiviteter.

I studien fra 2020 med barna/ungdommene selv uttrykte de at de følte seg isolert fra venner og sosiale aktiviteter og flere hadde følt seg nedstemt og deprimert. Flere av dem var redd for at de hadde en alvorlig sykdom. De skammet seg også over at deres symptom påvirket deres familier med tanke på jobb, økonomi osv. Flere av dem følte at de ikke hadde noen personer som helt forsto deres vanskelige situasjon og som de kunne snakke med.

De mente også at de ikke hadde fått noen sikker diagnose, at de ikke hadde fått tilstrekkelig informasjon om symptomene og at de ikke hadde fått behandling eller god nok behandling. Også barna og ungdommene mente symptomene hadde en fysisk årsak, men de var mer opptatt av at det også kunne være psykiske årsaker til symptomene enn deres foreldre var. De syntes selv at det å fokusere på noe positivt kunne avhjelpe situasjonen deres noe.

Fastlegene ønsket å følge opp disse pasientene selv og hevdet at det stort sett ikke var behov for henvisning til spesialisthelsetjenesten. Imidlertid henviste de likevel noen slike pasienter, spesielt hvis det var langvarige og diffuse symptom, om foreldre nærmest krevde det og hvis fastlegen trengte kollegial støtte. Den biopsykososiale metoden ble fremhevet som viktig i oppfølgingen.

Konklusjon:

Studien understreker kompleksiteten i smertetilstanden «funksjonelle gastrointestinale lidelser» hos barn og unge. Uttalelser fra pasientene selv, fra deres foreldre og deretter fastlegene understreker lidelsene disse pasientene og også deres familie opplever. Kommunikasjon mellom lege, pasient og pårørende virker å ikke gi den forklaring og trygghet som pasientene og pårørende etterlyste. Symptomene virker å bli forsterket av engstelsen og bekymringen som pasient og pårørende har for ennå ikke avdekket alvorlig sykdom. Dette resulterer i deres videre søken etter god behandling. Den biopsykososiale modellen bør være grunnleggende i den videre utvikling av retningslinjer for funksjonelle gastrointestinale lidelser hos barn og ungdom.

4. List of papers

I

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

Brodwall A, Glavin K, Lagerløv P. BMJ Open. 2018;8: e021066.

https://bmjopen.bmj.com/content/8/5/e021066.info

II

Understanding parents' experiences of disease course and influencing factors: a 3-year follow-up qualitative study among parents of children with functional abdominal pain

Brekke M, Brodwall A. BMJ Open. 2020;10: e037288.

https://bmjopen.bmj.com/content/10/8/e037288.info

*The correct order of the authors is: Brodwall A, Brekke M. See statement.

III

Children's and adolescents' experiences with functional abdominal pain: a qualitative study in Norway

Brodwall A, Brekke M. BMJ Open 2021;11: e048949.

https://bmjopen.bmj.com/content/11/9/e048949.info

IV

General practitioners' experiences with children and adolescents with functional gastro-intestinal disorders: a qualitative study in Norway

Brodwall A, Brekke M. Scandinavian Journal of Primary Health Care. 2021;39(4):543-551.
https://www.tandfonline.com/doi/full/10.1080/02813432.2021.2012347

5. Introduction

5.1 Personal experiences

During my 20 years as a general practitioner (GP), I often met child and adolescent patients with pain, often abdominal pain but also headache and muscular pain. Because I specialized in child and adolescent psychiatry, I worked at a pediatric department in a city hospital. There, I met child and adolescent patients referred from their GPs with the same pain symptoms. During the year I worked in the hospital that served 440 000 (now >500 000) inhabitants, there were 627 children and adolescents with FGIDs referred from the GPs in the surrounding region for further examination. As a child-and-adolescent psychiatrist in an outpatient clinic, I also met the same group of patients being referred from the GPs. Even if these patients had no organic pathology, their everyday function was reduced, and their families' function seemed to be affected. The GPs followed these patients from the first meeting, through a referral to specialists or hospital, after which they were referred back to primary health care without an organic diagnosis. These children and adolescents with FGIDs often had days or weeks absent from school and other activities. Their parents worried and stayed home from work together with them. The complex situation seemed to me to affect their lives negatively over time. I wondered if these children and adolescents learned to face other different difficult situations that probably turned up later in life? Would the children know that the body produces symptoms through life and that it is better to continue everyday life and duties instead of being afraid of dangerous diseases and staying home until recovering? The parents really seemed to try to do all the best for their children and adolescents. However, I thought they needed to understand how to tackle these situations themselves without seeing a physician at once. I also questioned if and how the children's and adolescents' symptoms affected the families? I was worried about these children's and adolescents' quality of life and I wondered what they needed to continue on without being disabled by the symptoms. I, thus, decided to investigate the families' and the GPs' experiences with children and adolescents suffering from FGIDs as well as the patients' own experiences.

5.2 History and prevalence of FGIDs

In 1958, John Apley, a British pediatrician, published his pioneering research on children with abdominal pain, a pain he called recurrent abdominal pain (RAP) syndrome (1). The definition of RAP was: "Children over the age of 3 years who had at least three periods of pain that persisted at least 3 months, with attacks continuing in the year preceding the examination. The symptoms were severe enough to affect the child's activities." No organic cause could explain the pain. Apley's monograph described the typical patient as a school-age child who had recurrent episodes of vague periumbilical abdominal pain. The child often was absent from school or went home from school because of persisting pain. Physical examination usually was normal, although mild, nonlocalized tenderness could be found or reported occasionally. Apley's original description proposed a simple etiology: "RAP was either organic or emotional in origin" (2).

Apley found that 10.8% of British schoolchildren had RAP, girls more often than boys (12.3% versus 9.5%). He reported: "As compared with other children, those with pains tend to be anxious, timid, fussy and over-conscientious, taking the ordinary difficulties of life (especially of school life) too much to heart." He stated further: "It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment" (1). The abbreviation RAP has since then been replaced by functional gastrointestinal disorders (FGIDs).

FGIDs define various combinations of chronic and recurrent gastrointestinal (GI) symptoms that do not have an identified underlying pathophysiology. The identification and classification of FGIDs are based on reported symptoms because there are no objective markers. The most widely accepted classification is based on the "Rome diagnostic criteria," a set of symptom-based guidelines for the assessment of FGIDs among children and adolescents. FGIDs are classified into different subcategories (3,4).

The criteria are discussed later in the manuscript.

FGIDs are a common diagnosis among children and adolescents with GI tract symptoms who present to primary care physicians or gastroenterologists.

In 2016, using the Rome III criteria, the prevalence of FGIDs among children and adolescents aged 4–18 years in the UK was 23% (having at least one FGIDs) (5).

A study from 2020 of Egyptian children aged 4–18 years using the Rome IV criteria reported a prevalence of 30.4% of FGIDs, with irritable bowel syndrome (IBS) as the most common type of FGIDs (6).

A systematic review from 2021 also using the Rome IV criteria with only exclusion criteria cohorts with known GI or organic conditions, concluded that the median prevalence of FGIDs for children from 4 to 18 years was 21.8% (range 19%–40%) (7).

Saps et al. found that 23% of children reported absence from school because of abdominal pain, with complaints persisting for at least 8 weeks in 24% (8).

FGIDs is a disorder often seen in children and adolescents. GPs, pediatricians and child-and-adolescent psychiatrists will probably quite often see patients with FGIDs in their practices. I also think that teachers ought to know something about FGIDs.

FGIDs are known to result from a complex interaction between biological, psychological and social factors (9–13).

5.3 The development of the Rome criteria

In 1978, the first global IBS criteria, the Manning criteria, based on adults' GI symptoms were introduced (14,15). The Kruis criteria, from 1984, underlined the importance of warning signs ("red flags") and the method for exclusion of organic disease in diagnosing IBS (16). The Manning and the Kruis criteria were the forerunners of the Rome I criteria, which international GI medicine specialists planned in 1992 to classify FGIDs. The Rome criteria are symptom-based guidelines for the assessment of FGIDs among children and adolescents. Important was to focus on the fact that the patients reported pain and discomfort although there was no chemical, radiological nor physical abnormalities (3,17).

Criteria for FGIDs in infancy, childhood and adolescence, the Rome II criteria, were introduced in 1999. The pediatric disorders criteria were arranged after main complaints reported by the child or the parents, in comparison to adult's organ-targeted classification (18).

Similar to Rome I, the Rome II criteria required that symptoms should be present for at least 12 weeks during the preceding 12 months (3,19). The term "discomfort" was added as an indicator and the criteria for the diagnosis of IBS was changed. Specific bowel habit subtypes were not in Rome II (3).

In the Rome III criteria from 2006, the pediatric criteria were divided into two groups: infants/toddlers and children/adolescents. The classifications were arranged based on complaints rather than anatomic regions. Subtypes of IBS were based on stool consistency rather than stool frequency and the bloating symptom was removed from the definition (3,20,21).

The Rome IV criteria came in 2016 with the definition of two new FGIDs (functional nausea and functional vomiting), IBS subtypes should be based on bowel habits on the day of abnormal bowel movements, the "discomfort" symptom was removed (3,22–25).

In the Rome IV criteria, symptom onset should be at least 6 months before the diagnosis, symptoms must be present 1 day/week during the last 3 months (3). The episodes should include all of the following:

1. Episodic or continuous abdominal pain that does not occur solely during physiological events such as eating and menses
2. Insufficient criteria for other functional GI disorders including IBS functional dyspepsia or abdominal migraine
3. After appropriate evaluation, the abdominal pain cannot be fully explained by another medical condition (26).

Koppen et al. emphasized the importance of the latest specific Rome criteria sets for FGIDs, which make a more accurate diagnosis possible (22). This helps limit further investigations of the children and also reduces healthcare costs (22). However, a difficulty with diagnosing FGIDs—especially in the youngest children—is the need for a correct description of symptoms such as nausea and abdominal pain and the pain history. This means that the children must be able to inform their parents verbally about the symptoms (22).

5.4 The definition of pain

The definition of pain (in general) was revised in 2020. This new version includes persons who are not able to express themselves verbally about pain, small children and animals. The subjective experiences of pain seem to be more emphasized.

IASP (International Association for the Study of Pain) Revised Definition of Pain 2020:
“An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.”
The definition is expanded upon by the addition of six key points.

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person’s report of an experience as pain should be respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.

- Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain (29).

5.5 Psychosomatic disorders and functional disorders

Psychosomatic disorders and functional disorders are often used to describe the same symptoms or conditions.

Psychosomatic disorders are defined as psychological conditions that lead to physical symptoms, usually without any medical explanation (30).

It could also be described as a somatic illness caused or exacerbated by mental stress and distress (31).

A prerequisite for psychosomatic disorders is that there is no underlying organic pathology (30).

Malt et al. state that the concept of psychosomatic disorders is also often used in a wider view as a term for the fact that psychological conditions have a central significance for a symptom picture and level of function, regardless of whether the underlying condition is functional or a well-defined biomedical disease (32,33).

Psychosomatic disorders are, however, not classified in the Manual of Mental Disorders (DSM-5) and just partly in the International Statistical Classification of Diseases and Related Health Problems (ICD-10). DSM is the Diagnostic and Statistical Manual of Mental Disorders. The manual is published by The American Psychiatric Association and is the official diagnostic criteria for mental illness in the United States, last updated in 2013. ICD is a classification and diagnosis system published by the World Health Organization (WHO). The ICD is periodically updated, last time in 1994. A new version (ICD-11) is expected in 2022. (34).

A functional disorder is defined as “a medical condition that impairs the normal functioning of bodily processes and remains largely undetected under physical examination, dissection, or by microscopic examination.” There should be no exterior appearance of abnormality. The causes are usually unknown or not understood (31).

Functional disorders are not included in DSM. In ICD-10, however, functional intestinal disorders unspecified and other specified functional intestinal disorders are included. I have used the term functional gastrointestinal disorders (FGIDs) in my study.

The history of psychosomatic medicine has roots back to ancient Greece and Hippocrates' thoughts of the health impact of the environment (35–37).

The term "psychosomatic" was introduced in 1818 by the first professor in psychiatry and psychotherapy in the western world, (Leipzig, Germany), Johann Christian August Heinroth (1773–1843). It was built on his understanding of the connection between and affection of body and mind (36). He was concerned with the holistic approach and is thought of as the biopsychosocial precursor (30). The biomedical model of disease was, however, the leading model until the end of the 19th century/beginning of the 20th century. This model concentrated on pathophysiology, disease, deviation and technical equipment in the examination and treatment. Sigmund Freud's psychoanalytic theory influenced the physician's views on and treatment of disease from the 1930s on (30).

In the past 80 years, psychosomatic medicine has focused on basic themes such as health and disease (38). From 1950/60 there was growing doubt about the biomedical model. The fact that a psychological factor played an important part in the regulation of pain produced a change in the understanding of pain (39,40).

In 1965 the "gate control theory" was presented by Melzak and Wall (40). This theory suggests that the spinal cord contains a neurological "gate" that either blocks pain signals or allows them to continue to the brain.

Later, many studies have documented the connection between the dysregulation of stress or challenging situations to individual's vulnerability to health problems (41–46). Individual persons experience different situations and events as stress. Trauma, abuse, frequent illness, fear, depression, anger, guilt, insecurity, family circumstances, etc. are some examples of stress triggers (47,48). In recent years, neurobiological research has revealed a relationship between stress and psychosomatic symptoms. Godoy et al. refer to the neural circuits of stress and their interaction with mediator molecules as important (49).

I would claim that today there is a broad acceptance of the fact that psychological and social factors affect health in human beings.

The prevalence of psychosomatic complaints in children and adolescents has been reported to be between 10% and 30% (50–52). The psychosomatic symptoms reported by children are often vague, diffuse and vary in location and intensity, making it more difficult to detect the actual pain. Abdominal pain, headaches, chest pain, fatigue, limb pain, back pain and breathing difficulties are typical psychosomatic pediatric symptoms (50–52).

5.6 The biopsychosocial model

Georg Engel, a specialist in internal medicine and psychiatry, formulated the biopsychosocial model in 1977. He meant that the understanding of disease had to be seen as a mutual influence between psychological, social, cultural, anatomical, physiological and biochemical factors (53). Thoughts, emotions and behavior were important in addition to social factors such as economy, social environment and cultural factors in understanding a person's medical condition or disease. Engel concluded: "The dominant model of disease today is biomedical, and it leaves no room within its framework for the social, psychological and behavioral dimension of illness." Disease in the biopsychosocial model was seen as a system consisting of the individual, his body and his surrounding environment. Engel criticized the thought that complex clinical conditions had just one single, often biomedical, cause. Instead, a multifactorial perception should be used. He also criticized the tendency that it was only the physician's and not the patient's way of understanding and interpreting the symptoms that was considered (38,53).

The model included genetic predispositions, central biological, somatic, affective, and cognitive processes that give feedback to and receive feedback from the peripheral autonomic, endocrine and immune systems (54,55).

The holistic approach with psychological and social intervention if necessary, in addition to medical treatment, was the basis for treatment based upon the biopsychosocial model (56–58). The model has been criticized by different researchers, especially for not giving a new understanding of the nonbiological factors (59).

The biopsychosocial model was adopted in 2002 by the WHO as the basis for the International Classification of Functioning, Disability and Health (60).

5.7 Treatment of FGIDs and other functional disorders in children and adolescents

The biopsychosocial understanding and handling of children and adolescents with FGIDs and their families are essential (61–63).

Organic causes of pain must always be excluded by the physician in the first consultations. Nonorganic causes of the symptoms should be discussed in parallel (64,65). Tidy states the importance of discussing the possibility for nonorganic causes of the symptoms at an early stage (64). The fact that the GP from the first consultation also considers nonorganic causes as a real alternative and not as a new solution if no organic cause is found will be important for the parents and the patients (64,66). It could be more difficult for them to support a nonorganic symptom alternative after all the examinations are completed (64). For children and parents to understand and accept a nonorganic cause for the symptoms, thorough information and psychoeducation about the stress mechanism are necessary. Kradin states that therapists often have the challenge that the common perception among people is that body and mind are separate entities and therefore respond independently (67).

The fear of cancer or other dangerous diseases ought to be seriously handled early (68,69). In my study, this was a current issue that will be discussed later.

Stressors are individual and change over time. Identifying and reducing stress factors in the patient's life is important. Predictability and the possibility for the patient and parents to understand and control the symptoms will lead to an experience of security and a reduction of symptoms (70). Family conversations/family treatment, cognitive behavioral therapy or other psychological treatment usually is necessary (71).

In addition, the school and the patient's teachers often need information and psychoeducation about FGIDs. They need knowledge about functional disorders and a thorough explanation of pain mechanisms. Teachers also need to understand that to the child these symptoms are real and genuine (64).

Patients, parents, as well as teachers, should be informed that an important part of the FGIDs' treatment is to continue normal everyday activities and routines including attending school. It must be explained that staying home from school most certainly will not improve the symptoms but maintain the pain and delay the treatment (64,72). The advice is clear: "pain during class should be managed through continuation of the usual routine" (73). However, it is also important to show respect to all persons, including children and adolescents with FGIDs or other functional disorders. The child has a difficult situation and needs help to recover.

If the symptoms are long-lasting and there is little progress in the treatment, especially if the symptoms are severe, the GP must consider referring the patient to a hospital or specialists (74).

The patient's total situation should be considered by the physician together with the parents. A multidisciplinary approach to patients with FGIDs with the cooperation of different professions including schools often could be useful (11).

5.8 The Norwegian GP scheme

The organization of Norwegian GPs is based in the Norwegian GP scheme from 2001 (75,76). There are about 5000 GPs in Norway (77). In 2020, 44.8% of GPs are female and the average age of GPs is 47.2 years (77).

All inhabitants who are registered in the National Registry as living in Norway have the right to a GP. The Norwegian GPs today have on average 1100 listed patients each with a maximum of 2000 patients (78).

The GPs get a certain amount of money for each patient a year from the municipality, per capita grants (about NOK 500). This is supposed to cover some of the ordinary operating expenses for the office. The GPs also get a refund for each consultation, as well as for blood tests and certain other procedures. The patient pays a user fee of NOK 160/212 for a GP appointment but children up to 16 years go for free (79). The appointment with the GP lasts about 15–20 minutes.

Norwegian GPs have a gatekeeper function and refer the patient to secondary health care if needed (80). After completed examination or treatment, the patient is referred back to the GP with an epicrisis (80–83).

This list system is meant to create continuity and predictability for the patients as well as the physicians. Often, several family members have the same GP for many years. It makes it easier for the GP to consider the situation over time, to have an overview of examinations and treatments and to give psychoeducation and information. The disadvantage is that this can delay referrals to the examination of potentially serious diseases because the GP is the only physician who has seen the patient (84–86). To the GPs, it is a great responsibility to be the patient’s only physician over time.

In 2019 there was an evaluation of the Norwegian GP scheme that indicated that GPs over time have more administrative work tasks and less time for patient treatment, which is a dangerous development (87–90).

6. Aims of the study. Research questions

The overall aim of the thesis was to provide new knowledge about FGIDs in children and adolescents. The thesis particularly focuses on parents’, patients’ and GPs’ experience with FGIDs and thereby explores the impact of this condition on the family and the patient. We were interested in exploring what the children, adolescents and families experienced as useful and what they thought they needed to improve their situation. The GPs' thoughts about treating children and adolescents with FGIDs were also interesting for us.

The following research questions were addressed in papers I–IV:

Paper I:

a. Do FGIDs in children and adolescents impact their parents and siblings and how?

b. What do the parents think is the cause of the symptoms?

c. What do the parents think could improve the symptoms and the family's situation?

Paper II:

a. How have the children's and adolescents' FGIDs influenced the family over time (the last three years)?

b. What were the causes of the children's/adolescents' FGIDs in the last three years?

c. What did the parents think had helped the children/adolescents with recovery or improvement of the FGIDs?

d. If the children/adolescents had not improved, what did the parents think had contributed to that?

Paper III:

a. How have FGIDs affected the lives of children and adolescents?

b. What were the children's and adolescents' thoughts about if and how their FGIDs affected the family?

c. What did the children and adolescents think could be the cause of the FGIDs?

d. What did the children and adolescents think had helped them or could have helped them in recovery or improvement?

Paper IV:

a. What were the GPs' experiences with treating children and adolescents with FGIDs?

b. What were the GPs' views on the impact of the family on the children's and adolescents' FGIDs?

c. What did the GPs think about referrals of these patients to hospital/specialists?

d. What did the GPs think was their task when these patients returned from hospital?

e. What types of approach and treatment did the GPs think these patients and their families needed?

7. Material and methods

7.1. Participants and data collection

7.1.1 Paper I

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

Participants

Parents of children and adolescents who had been examined in hospital because of episodes of FGIDs were invited to participate in the study. Inclusion period: February 2016 to June 2016, location: Drammen hospital, Child and Adolescent Department, Vestre Viken Health Trust (VVHF). A nurse in the hospital carried out the face-to-face recruitment consecutively among eligible families. She handed out written information and obtained the participating parents' phone number. The children turned out to be 6–13.5 years old, seven boys and seven girls. Twenty parents were invited; although all agreed to participate, six parents withdrew from the interview appointments without giving any reason. Thus, ten mothers and five fathers (one couple) were interviewed. Only two of the recruited parents lived without their spouse, and 11 of the participants were Norwegian. Four foreign parents had lived in Norway for several years. They mastered the language well. I contacted the parents by telephone to plan the interview. Data saturation had been reached after 14 parents (13 individual parents and one couple) and the recruitment stopped.

The participants were asked if they accepted to be contacted for a new interview in three years. All parents were positive.

Interviews

All interviews were conducted by AB. The participants in the study were informed that the interviewer was a physician, however, she had no therapeutic responsibility in the research setting.

In 2016, the interviews were held in localities chosen by the parents: in the family's home, at the author's office in the hospital or at the parent's workplace. One interview was conducted by telephone. The audiotaped interviews lasted 45–75 minutes. The only exclusion criterion was an inability to communicate in the Norwegian language.

7.1.2 Paper II

Understanding parents' experiences of disease course and influencing factors: a 3-year follow-up qualitative study among parents of children with functional abdominal pain

Participants

Three years after the first study, the same parents were interviewed again, all fifteen parents accepted the invitation. Inclusion period March 2019 to August 2019. Their children and adolescents were now 9–17 years old. I interviewed ten mothers and five fathers (one couple). There were no changes in the parents' civil status. One family had moved to another city in Norway.

Interviews

All interviews were conducted by AB. As in 2016, all interview subjects knew that the interviewer was a physician, however, she had no therapeutic responsibility in the research setting. Written information was sent out to the participants.

As in 2016, the interviews were held in localities that were chosen by the parents: in the family's home, at the author's office in the hospital or at the parent's workplace. Four interviews were conducted by telephone because the parents had moved or were on vacation. The audiotaped interviews lasted 30–60 minutes. The only exclusion criterion was an inability to communicate in the Norwegian language.

7.1.3 Paper III

Children's and adolescents' experiences with functional abdominal pain: a qualitative study in Norway

Participants

The children and adolescents of the interviewed parents were interviewed. Inclusion period March 2020 to September 2020. Twelve of the fourteen children and adolescents, six girls and six boys, aged 10–18 years agreed to be interviewed. Nine of the children had Norwegian parents and three had parents of foreign origin who had lived in Norway for several years. Two of the children lived with a stepparent. Eleven children had siblings; eight had one sibling, two had two siblings and one had three half-siblings.

Interviews

All interviews were conducted by AB. All interview subjects knew that the interviewer was a physician, however, she had no therapeutic responsibility in the research setting.

Written information had been sent to the children and adolescents or to their parents, dependent on the participants' age. I explained to them the study at the start of the interview and answered their questions. Because these were young persons, their understanding and trust were emphasized.

All interviews were conducted as video conferences due to the COVID-19 pandemic. The audiotaped interviews lasted 25–60 minutes.

7.1.4 Paper IV

General practitioners' experiences with children and adolescents with functional gastrointestinal disorders: a qualitative study in Norway

Participants

GPs who had their practices in the region where the interviewed families lived. These were not the GPs of these specific patients. Inclusion period September 2020 to November 2020. Fourteen GPs (from the region GP list) were contacted and asked to participate, twelve GPs accepted the invitation, two GPs withdrew without giving any reason. Data saturation was reached after twelve GP interviews; recruitment, therefore, was stopped. Eight female GPs and four male GPs were interviewed, the age varied from 36 to 67 years. This was a strategic sample based on age, gender, urban or rural practice and predominance of immigrants or Norwegian inhabitants in the practice.

Interviews

All interviews were conducted by AB. The GPs knew that the interviewer was a physician who had worked as a GP for several years but had no therapeutic responsibility in this setting. All interviews with the GPs were conducted by telephone because of the COVID-19 pandemic but also to respect the GPs' busy day. The audiotaped interviews lasted 16–40 minutes. Written information about the study had been sent to the GPs before the interview

7.2 Interview guide

A semi-structured interview guide was developed for each study comprising 10–13 open-ended questions and additional follow-up questions that allowed the interviewer to probe more deeply. The questions were developed after discussions and agreement, in the first study together with two experienced academics; a physician and a public health nurse, in the second to fourth studies with an experienced academic, a GP, all of whom had experience with child

and adolescent patients. After two interviews, the guides were evaluated, and some small modifications were made.
Appendix: Interview guides

7.3 Study design and data analysis

A qualitative design with individual interviews was chosen.
The interviews in all four studies were audiotape recorded and transcribed me (AB) the same day as the interview took place. Qualitative content analysis was conducted based on work by Graneheim and Lundman (91). Both/all authors read the transcripts individually several times. The interpretations and analyses were discussed to achieve a common understanding. Disagreements were discussed until there was a solution that could be agreed on (91). The interview texts were sorted and coded, abstracted into sub-themes which through reflections were unified into themes. The biopsychosocial model also provided a basis for all four studies.
No software tool was used for the analyses.
The study design and data analysis will be discussed and described in more detail further in "Methodological considerations" (Section 9.1).

8. Summary of results

8.1 Paper I

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

After having been referred to hospital and no serious diagnosis are found there, children and adolescents with FGIDs often come back to their GPs. Some of the parents reported that they were worried about the fact that the children's and adolescents' symptoms were a serious disease not yet detected. They often felt dissatisfied because they had not received information at the hospital about how to manage their children's and adolescents' symptoms. The parents stated that they wanted a somatic explanation, a solution and treatment of the FGIDs that could reduce or remove the child's symptoms. They were frustrated because they were left without any guidance about how to manage their child's and adolescent's FGIDs. As the situation was now, the parents felt that they had to find their own way of helping the child and managing the whole pain situation. Some of the parents had tried to explain to the children and adolescents about the connections between somatic sensations and feelings. The parents also wanted closer contact with the physician to discuss the difficulties with having a child or adolescent with FGIDs.

8.2 Paper II

Understanding parents' experiences of disease course and influencing factors: a 3-year follow-up qualitative study among parents of children with functional abdominal pain

In the three years since the original interview (2016), nine of the children (4 girls and 5 boys) had recovered from FGIDs, and in three (1 girl and 2 boys), the pain persevered. In two of the children, the situation was unclear. "Recovered" was defined as having no complaints and having returned to school and other activities. The age of the recovered boys was 10.5–17 years, for the recovered girls 8.8–15 years. The ages of the three children still in pain were 9, 10 and 11.5 years old.

No clear reason for recovery was determined for six of the children and adolescents who had recovered from FGIDs. Feedback from the parents in the research interviews was a desire for a diagnosis for their children's and adolescents' FGIDs. They also needed to discuss the FGIDs situation with a physician more often and they expressed an unsatisfactory cooperation with the school.

8.3 Paper III

Children's and adolescents' experiences with functional abdominal pain: a qualitative study in Norway

In 2020, twelve children and adolescents were interviewed about their experiences with having FGIDs. They were 10–18 years old, their parents had been interviewed about the same topic in 2016 and 2019 (Studies I and II).

Eight children and adolescents (four boys and four girls) had recovered from their FGIDs; four (two boys and two girls) had improved symptoms. Two of the parents' children did not participate. Their parents informed me that their child had recovered from FGIDs. They did not specify why the child did not participate in the study.

All the children and adolescents stated that it was important for them to keep up with their sport activities and hobbies as well as keep in contact with their friends. Focusing on positive activities made them less sad and could reduce the FGIDs. However, three of the adolescents had been absent from school for weeks and months. They reported that they were sad and depressed and felt isolated from the world outside. Many of the children and adolescents reported a major concern that their symptoms could be cancer. Most of them claimed that their symptoms were of organic cause. They underlined the importance of closer contact with their physicians with information and psychoeducation about FGIDs. Some of the adolescents and also some children wondered if the FGIDs could represent some difficulties such as having something to do with friends, dread of exams and other situations at school.

8.4 Paper IV

General practitioners' experiences with children and adolescents with functional gastro-intestinal disorders: a qualitative study in Norway

The GPs had consultations with 1–10 children and adolescents (aged 5–18 years) with FGIDs each month.

The GPs stated that children and adolescents with FGIDs were a patient group that was best served by being in primary healthcare service. The GPs thought it seldom was necessary to refer these patients to hospital or specialists. They stated that they had the qualifications to handle and treat young patients with FGIDs. Often the GPs had to inform and reassure the parents and the patients that FGIDs were not cancer or another serious disease. Teaching the parents and the patients the connection between body sensations, body reactions, emotions and mental symptoms was an important task for the GPs. The biopsychosocial model was essential in understanding and treating the FGIDs' patients. The GPs were also aware of the fact that mental symptoms could have a connection with the patients' FGIDs. Being the family physician over several years was also seen as important by the GPs. Symptoms seen in one or more family members could then be observed and followed over time. The GPs stated that the focus should be on normality and mastering everyday life.

8.5 Results from Studies I–IV

Children and adolescents with FGIDs as well as their parents called for a diagnosis of the disorders, an explanation and more information about treatment that could lead to recovery or reduction of the symptoms. Many of the participants (Studies I–III) thought that the symptoms had an organic cause, some of them were afraid of undiscovered serious disease and this fear influenced their lives. The GPs argued that patients with FGIDs belonged in primary health care and that the biopsychosocial model was important for understanding the symptoms and for recovery.

9. Discussion

9.1 Methodological considerations

In qualitative research, the study design, the conducting of the interviews and the analysis of the material are important to secure the scientific quality of the research. It is also essential that the findings and assessments in the study are understandable and transparent to the readers and other researchers (92).

I will discuss:

- reflexivity
- validity
- reliability

to evaluate the trustworthiness of the study.

I will also discuss the qualitative interview as a research method.

The use of these interviews when the subjects are children, adolescents and colleagues will also be problematized.

9.1.1 The qualitative research method

Qualitative and quantitative research are based on different research systems (93). Primarily, the researcher must decide what to investigate and dependent on the research question, the method is then chosen.

Quantitative research methods often have a hypothesis from earlier research and raise the research question of whether the hypothesis is confirmed. Quantitative methodology uses numerical data, hard facts, mathematical and statistical methods. Graphs and tables can be built up to explore the data exactly (94).

Qualitative research is defined as "the study of the nature of phenomena," including "their quality, different manifestations, the context in which they appear or the perspectives from which they can be perceived," but excluding "their range, frequency and place in an objectively determined chain of cause and effect" (95). This can be expressed in an easier way and with fewer words: "Qualitative research generally includes data in the form of words rather than numbers" (96). International literature also defines qualitative methods as "naturalistic inquiry" or "interpretive inquiry" (97,98). The method is based on theories of interpretation (hermeneutics) and human experience (phenomenology) (99).

Qualitative research has theories that characterize what are interesting questions within a particular subject (100). Kvale and Brinkmann state that when the research focuses on diverse features of the human experience and the research question is expressed with "how," it is often useful to choose a qualitative design (101). This research model often also concentrates on the "why" rather than the "what" of social process. Interviews, observations or other documented material are often used as research methods and are conducted to explore in-depth processes. The experiences, behavior, intention and attitudes of the everyday life/natural setting of human beings are elements that are explored, often to get an in-depth insight into a problem (102–104). "We seek through research methods to identify how society in the broadest sense is created through action, interaction and opinion formation," Tjora states (100). The researchers' own experiences also play a part in qualitative research and can affect the interpretations and the results (100). This is discussed in more detail in Sections 9.1.3 and 9.1.4.

9.1.2 Interview as a research method

In qualitative research, the research interview works as an effective investigation instrument to explore unknown parts of medicine, especially within education and practice (105). Through interviews and conversations, sensitive in-depth description is given directly to the researcher from the participants. The spoken words, the body language as well as the interpersonal social interaction between interviewer and participants give other perspectives of the research questions compared with a quantitative research approach with statistical methods and numerical data.

Face-to-face interviews were originally chosen as a method for collecting all data in my studies. The first two studies (2016 and 2019 with the parents) were held as personal meetings in localities that suited the parents. However, because of the COVID-19 pandemic, we had to change the interview method for the last two studies. The interviews with the children and adolescents were therefore held by video (Skype, join.nhn), and the GPs were interviewed by telephone.

9.1.2.i Personal interviews, telephone interviews, video interviews

Within qualitative research, the in-person interview is regarded as the highest standard of interviewer methods (106,107). A study by Krouwel et al. (108) compared in-person interviews and video interviews and found some small differences. The face-to-face interviews differed from the video interviews in producing more words, having deeper discussions and lasting longer. In contrast, the video interviews were shorter and had lower costs (109,110), however, technical issues and technical training were needed. There also was a possibility for disturbance by family members, colleagues and pets (110–113).

Krouwel et al. stated that video interviews could be the only possibility for continuing the research and handling the interviews in periods or situations that make it impossible or unsafe to conduct in-person interviews (108,114). The above-reported situation was what I experienced when the COVID-19 pandemic with lockdown made me change the interview method for the last two studies. Primarily, I had wanted to conduct in-person interviews because visual communication and body language are important information. I also thought in planning the study that the interview subjects would feel more confident when meeting the interviewer live and thus would give the most honest and comprehensive information.

I think it was an advantage that we were able to use the same interview method in both studies of the parents (Studies I and II). I then could use and compare the nonverbal expression and communication. The parents also were familiar with the interview location from the previous meeting.

Because in-person interviews were impossible, I considered telephone interviews to be the most effective way to interview the GPs, concerning time and organization for the colleagues. Studies comparing qualitative telephone and face-to-face interviews showed that the face-to-face interviews were longer, and the participants were the dominant speaker for more of the time, compared with telephone interviews (100,115). There could be several explanations for this; a telephone interview would probably follow the interview guide more exactly, be less private and leave less room for small-talk.

Vogl interviewed children 5–11 years old with both telephone and in-person interviews (116). The telephone interviews reduced the possibility for observing body language and personal contact. However, that study argues against previous views that semi-structured telephone interviews were not suitable for qualitative research and with children.

Internet-based or paper-based questionnaires would be another possible method in my study. However, it would not then have been possible for spontaneous follow-up questions that could dig deeper into the topic. I would also have lost the body language in addition to the participants' voices, which often are a part of the interpretations of the interview. Ebert et al. found that web-based questionnaires had lower response rates, had somewhat lower numbers of missing values and had lower costs than paper-based questionnaires (117).

9.1.2.ii Interviewing children

Conversations and interviews are important parts of GPs', pediatricians' and child-and-adolescent psychiatrists' approaches to their young patients. The American Association of Pediatrics has for decades (the 1970s–1980s) used the expression "new morbidity" meaning behavioral, developmental and social function problems, as well as prevention, early detection and management of these problems. Since 1987, behavioral teaching has been a part of pediatricians' training programs. The quality of the conversation and the interviewing skills can be crucial for the physician for accurate information about uncovered difficulties in children and adolescents (118–120). In Norway, social pediatric and preventive pediatric medicine are part of the specialist education (121).

For years through my work as a GP and later as a child-and-adolescent psychiatrist, I have daily had conversations with children and adolescents, which have given me valuable experiences for these interview studies. Other researchers are usually adults and must consider how to "reach in" and familiarize themselves with their young study participants. Children's intellectual/cognitive level, coping strategies, social abilities, willingness and motivation to share their problems must also be considered. The children need to be informed about their role in the interview/study and the purpose of the interview/study to maintain trust in the researcher (122,123). Children and adolescents have special rights as patients (124). The language used in the interviews must be adapted to children of different ages. The structure of the interview, how the questions are raised and where the interviews are conducted are also important factors. The children's understanding of the information and interview questions is essential for the quality of the research results (122,123). Brown and Lamb underline the influence of the children's developmental level on the accuracy of the answers in the interviews (125). Older children have a more developed ability to communicate, especially concerning details. The child's choice of words and their vocabulary in these conversations about problems are also limited. The researcher must also remember that it could be challenging for the children and the adolescents to talk about the problems asked (126,127).

Open-ended questions are often good tools for the children to elaborate on views and themes about themselves and their families. A predictable and safe interview conversation is important in child interviews. As mentioned above, I had to make sure that all the questions were understood by asking the children and opening up for further explanation. In addition, school-aged children often want to please the interviewer, and therefore answer with what they think the researcher wants to hear (128). If this was suspected, I had to explain or approach the problem/question from another angle.
The children in my study were not younger than 10 years old. I noticed, however, that a couple of the youngest children who had recovered from the abdominal pain had difficulty in remembering details about the pain period. The children should be informed that answers such as “I do not know” or “I do not remember” are also acceptable answers (129).
To create a safe interview situation, I informed the children in the research letter as well as orally that one of the parents could be with them during the interview. Three of the youngest children agreed to this and brought their mothers (discussed in Section 9.1.3).

9.1.2.iii Interviewing adolescents

Interviews with adolescents have components in common with interviewing children, but as their developmental age, intellectual, social and linguistic skills are on another level, the conversations must be adapted to this situation. Confidentiality must be explained to all age groups, but adolescents will often demand more accurate information about this. Information and transparency about the limits of confidentiality are required to obtain correct information about the problems from the youths. This is as important here as in the therapy room (130). All interviewees must be treated with respect. Adolescents are often concerned that they are no longer children and want a more mature approach. They want to be listened to and are concerned about the fact that the interviewer understands what they are trying to say. It is easier to control the conversation about the intended health subject when the adolescent feels secure and taken care of in the interview. To summarize the main statements at the end of the interview and have the adolescent’s acceptance of them, I think could be wise (131).

The adolescents in my study were interviewed alone without parents, except for one participant who for practical/technical reasons had a parent nearby. The adolescents were informed about the possibility of bringing the parents, but they did not ask for that. It is probably easier for the adolescents to discuss sensitive issues being alone with the interviewer. Because many health problems might be connected to behavior, difficult events or social problems, adolescents might experience this as shameful or challenging (132).

In my experience, privacy in the interview session is more crucial for adolescents than other age groups for informing correctly about their situation (133).
For interviewing adolescents about psychosocial problems, there is a form, HEADS (Home, Education, Eating, Activities, Drugs, Sex, Safety and Self-harm) that can be used in hospital as well as in an outpatient department (134,135).

9.1.2.iv Interviewing colleagues

The interviewer herself is a physician and has been a GP for about 20 years, now working as a child-and-adolescent psychiatrist. As such, the interview study with the GPs was an intercollegiate conversation. The ethical balance between the two doctors is important here with emphasis on respect for the colleague's opinion and the way of treating the tasks. It could have been more difficult for the GPs to reject the invitation when it was a colleague who invited. However, the invitation was not presented directly to the GP in person but through the office personnel and not all invited GPs did reply to the request. Some of the GPs could have felt freer to answer the questions if the interviewer had no medical education or if they had answered on a paper-based or web-based questionnaire. On the other hand, I viewed my medical education as an interviewer as an advantage because the reflections became more in-depth and more aspects were highlighted. Knowing the GPs' timetables, I knew that it was important to keep to the stated time for the interview, in respect of the GPs' busy day.

Some of the GPs responded that they appreciated the conversation and that these issues were focused on.

I did not take notes during the interviews because I wanted to focus on the participants. The audio recording made this possible. As mentioned in Section 9.1.8, I made some small notes after the interviews to remember details that were not noticeable in the audio recording.

9.1.3 The qualitative research interview

In the 1970s and 1980s, qualitative research emerged in clinical research and thereby qualitative interviews of different models/types were presented. This changed the data collection system and introduced another level of the collected information (136). These interviews brought in information from the participants in everyday language, in contrast to the usual research language. The interviews explored the participants' views, beliefs and how they experienced their lives (93,101).

Our interview questions referred to the parents', children's, adolescents' and also the GPs' experiences with FGIDs. We explored the feelings, thoughts and situations with the phenomenon of FGIDs. We were not interested in numerical data in the studies. A qualitative design with semi-structured questions with a phenomenological approach was therefore chosen as the research method.

The flexibility and the various possibilities of qualitative research methods are often seen from a science theory point of view as one of the greatest research advantages (137). In qualitative research, the choice of research focus and the inclusion strategy can be changed during the research process, as new and unexpected knowledge might emerge during this process. These new nuances of knowledge can create the basis of new issues that will be investigated further in the research. If all plans and choices in qualitative research are done in advance, it will threaten the quality of the research, as opposed to quantitative scientific research (137). My curiosity in finding new information about FGIDs was the reason that I continued my research after the first study. The parents' experience with their children's and adolescents' FGIDs opened up new information and new theories. I, therefore, chose to continue with a follow-up study of the parents. Later, I became curious about how the children and adolescents themselves had experienced their situation. And last, I wondered about the GPs' experiences and thoughts about their young patients with FGIDs.

The quality of qualitative research will among other things depend on the quality of the interview. The researcher's personal ability in interviewing the participants will influence the information that can be collected. The questions must be handled in an equal way so that all participants are asked about the same areas of information. Preparing the interview in advance is important. The participants should be informed about the format and purpose of the study, how long it is expected to last, the terms of confidentiality and how to get in contact with the researcher. Time to become familiar should be prioritized so that a certain trust between researcher and interview subject can be built in a respectful way (101,105,138–144).

A suitable location for the interview will make the interview situation more convenient. The interviewee must feel safe to elaborate on sensitive questions. Interruption by other people, pets or telephones must be prevented (110,112,138).

The participants in my studies were asked where they preferred to be interviewed. Most of the personal interviews were in my office, however, some were in the participant's office, home or another suitable place (145).

All the parents accepted a new interview three years later. I took this as a sign that the interview situation had not been too difficult for them.

The presence of the parents during the interviews of some children could have influenced some of the answers, particularly where the parents' involvement in the pain situation was explored (146). However, these children appeared relaxed and not nervous during the interview. Whether the mother's presence made the situation better for them is not possible to answer but as long as they asked for it, I of course accepted her presence. Children's problems with shyness and embarrassment may be positively as well as negatively influenced by video interviews. Most children today are, however, used to this type of media tool. Interviewing them sitting in their homes or other familiar locations could be helpful to them (122,123).

9.1.4 The role of the researcher and the participant—reflexivity

In qualitative research, the researcher is an instrument in the research process, especially in the data collection. The relationship between the researcher and the participant has several facets and is crucial for the collection of information to succeed (147). Karnieli-Miller et al. state that there is a hierarchical relation of power between the researcher and the participant. This power may vary according to different variables, such as the researcher's personality, the role of the participants, and the research goal (148).

The researcher being a physician or a nurse in a medical study can affect the balance of power in the study. Having medical competence or being a professional as a researcher in a project can be an advantage, at the same time such a position may prevent other aspects and perspectives from emerging (137,149).

The fact that I—a physician—carried out all interviews in my studies could probably have influenced the interview situation and the answers. The participants were told that I was there as a researcher and not as a physician. I could not give them any benefits regarding investigations or treatment by taking part in the study.

There was, however, a chance that especially in the interview study with children and adolescents, they could think they should be nice and positive to the researcher and answer the questions "correctly" to gain something. The given information that there was no advantage in answering "correctly" therefore also became important (153).

The roles between the researcher and the researched are primarily asymmetric, however, the researched after all also have their own agenda (148,151). The participants have the right to decide and control what to share with the researcher. This will influence the results of the study and thereby the quality of the research. This fact can change the power in the research balance (151,152). The balance of power can also be affected if the participants during the interview change their minds and want to stop the interview. The researcher depends on the participants' sharing of experience. The participants' opinions and choices must always be respected, and their decision must be implemented (100).

The participants in my studies were informed that the interviewer as a physician was used to talking about health and all kinds of symptoms, which probably made it easier for the parents and the children/adolescents to explain their situation. This is especially important concerning sensitive information. Most of the parents and the patients talked quite frankly about the pain problems. In the first study in 2016, the children had recently been to hospital and most of them still had FGIDs in the interview period. In some of the interviews, some of the parents asked if I, the interviewer, had experience with and had some advice about their children's symptoms. Having worked as a GP and child-and-adolescent psychiatrist for several years has given me valuable experiences about how to treat such situations. However, trying to be neutral toward these questions and at the same time being able to continue the interview, was a challenging balance. Twice I answered the parents that I could try to give general advice after the last question when the audio recorder was stopped (96). Important for me though was not to answer as their GP or pediatrician but tell them to contact their regular GP for more advice (discussed in Section 9.1.8).

In the follow-up study three years later, the children's/adolescents' symptom burden was reduced, the situation, therefore, was better for the parents. One of the parents remarked that the interview in 2016 had been a constructive and helpful situation for him/her because it helped just talking about the situation to somebody with medical training. Talking about sensitive questions could evoke reactions such as crying. That happened a few times during the parents' interviews. Researchers interviewing people in a difficult life situation must be prepared for reactions and strong emotions in the participants. I think showing emotions must be thought of as normal when parents give sensitive information about their children (142). Even if the participants have agreed to participate in the study and have been informed about the study questions, they will probably be unprepared for what they may reveal and for emotional reactions during the interview. In this way, the participants, as well as the researcher, will experience that the qualitative research process is not predictable and that they could be unprepared for the situation (147,154).

My experience is that it is important to practice conversation techniques in advance. It is also important to try to imagine reactions from the participants during the interviews and plan some kind of technique in case of emotional reactions. To show empathy and to continue the interview after a short pause did work for me (107,155–159). However, stories about children in pain and desperate parents who are crying or showing other types of emotions often will affect the researcher emotionally. These reactions could challenge the researcher's role and the balance of power in the interview. They could risk the danger of being emotionally drained and exposed to the stress of compassion (147,160–163).

9.1.5 Saturation

In 2016, I interviewed 15 parents (one interview with both parents). After these 14 interviews, I did not get much new information and the interviewing was ended. In 2019, I interviewed the same parents as a follow-up, and in 2020 I interviewed these parents' children and adolescents. This is written in detail in Section 7.1.1-7.1.3 In Studies II and III, the sample size was decided in advance because I used the same persons in Study II and the children and adolescents of the interviewed parents in Study III.

In 2020, I interviewed 12 GPs. After these 12 interviews, I did not obtain much interesting and new information from the GPs and the data collection was ended (164).

In qualitative research, the definition for sample size is "saturation." Saturation occurs when "the researcher no longer receives information that adds to the theory that has been developed" (164).

Sample size and saturation have been discussed by researchers over time. Morse defines saturation as "data adequacy", collecting data until no new information is obtained" (164) and that the more information gained from each participant, the fewer number of interviewees are needed (164).

Malterud et al. proposed the concept "information power" to guide adequate sample size for qualitative research. Information power indicates that the more information the sample holds, relevant for the actual study, the lower the number of participants needed (165).

Emmer states: "It is not the number of cases that matters, it is what you do with it" (166).

The fact is that you never know if the next interview would give new, interesting information or nuances of the information. There will always be a chance to lose some information when the interviewing is stopped (100).

When planning a qualitative research study, it will be necessary to have an approximation of the sample size. Deciding the final sample size must be continuously assessed during the research process (166,167).

I discussed sample size/saturation with the co-authors of my studies. We agreed that the conducted interviews provided comprehensive information about the themes I studied. I, therefore, had much material about the problems of FGIDs and it was important for me to do a thorough analysis and work with the already existing material. However, I also think further interviews might have given new nuances.

9.1.6 Samples

In qualitative research, a sampling plan is made that should make it possible to collect participants who give valuable information to understand the researched topic. Describing and explaining the sampling strategies is important for the quality and the validity of qualitative research (168–170). It could be a challenging task to "find" and recruit participants that suit the study. However, as said in Section 9.1.5, in qualitative research it is not the exact number of participants that is important but the fact that sufficient information about the topic has been revealed (137). The answers especially on the follow-up questions often give new perspectives to the researched topic and further information is wanted. This results in new participants being contacted for new interviews (170).

Method textbooks often give little information and advice about the recruitment process and the expected number of participants (170,171). Careful work by the research team in advance is crucial to succeeding with the recruitment. Important could be different types of preparatory work such as identifying qualified patients, fixing recruitment material and informing other researchers (170,171).

Study I: Drammen hospital, Child and Adolescent Department, covered in 2015 about 440 000 people. That year, 568 outpatients were referred to the department because of abdominal pain that had lasted for weeks and had no organic diagnosis.

Recruitment: Parents of children aged 6–13.5 years who had been referred to and examined at the outpatient department because of FGIDs. The parents were orally informed about the study and given written information by one hospital nurse. It was face-to-face recruitment.

She also obtained the parents' telephone number. Exclusion criteria: The parents did not speak and understand Norwegian. There was no translator connected to the study. Twenty parents were contacted by telephone by me (AB) for an interview. Six parents later withdrew from the appointment without giving any information why. We have no characteristics of the parents who first accepted and later withdrew. The recruitment took about three to four months (including holidays). Written information was sent, the parents had to give written consent.

Study II: A 3-year follow-up study. The parents (15 persons) were interviewed three years after their first interview. These parents had participated in Study I and had then accepted being contacted for a new interview after some years. I contacted them by telephone again just as last time. Written information was sent, the parents had to give written consent.

Study III: The children/adolescents of the interviewed parents were interviewed. I contacted the parents and asked if they accepted a request about interviewing their child and adolescent. Adolescents over 16 years of age had to answer the request themselves. Written information was sent, and the parents and/or adolescent had to give written consent. Twelve of the 14 children and adolescents were interviewed—except for one child with other physical challenges and one child who did not want to participate.

Study IV: The interviewed GPs worked in the region that "belonged" to Drammen hospital where the study started in 2016. This was a strategic sample based on age, gender, urban or rural practice and predominance of immigrants or Norwegian inhabitants. The average age of GPs in Norway in 2020 was 47.2 years (77). The GPs in my study were 36–67 years old. The GPs characteristics are given in Section 7.1.4. Written information was sent, the GPs had to give written consent.

It might have been more difficult to recruit GPs from regions farther away, (west-north). The GPs were told that the children and adolescents with FGIDs and their parents lived in the same region as the GPs worked. Even if the subjects covered all geographic regions, I think it was more interesting for the "local" GPs to participate.

In addition, in Study IV there was a predominance of female GPs (eight females, four males). The two GPs that withdraw from the study were male GPs. In Norway in 2020, 44.89% of GPs were female (Section 5.8). There are about 50 percent female and male GPs in the participating health region (77,178,179).

There could be several reasons for the slightly different distribution, but as the sample is small it is impossible to speculate whether this is random.

Different factors, often concerning convenience and economy, can influence the willingness to accept the invitation to a research study. These may include geographic location of the interviews, which could be affected by expenses such as parking fees and tickets to transport as well as childcare expenses (172). In my studies, I asked the participants what location suited them best for the interview. I think it could have been decisive for some of the participants to accept the interview that I came to their workplace, home, etc., both concerning time and expenses.

There were more female participants than male participants in my studies (Study I, II and IV). In Studies I and II there were 10 mothers and 5 fathers. The traditional gender pattern with a mother taking care of children and the house could still influence the gender distribution (164,170,172–175).

What and how information about the research is provided to potential participants I think could play a part in accepting an interview invitation. The information that was handed out in our studies was a personal letter about the study and information about ethics and informed consent. The information letter ought to be as short and clear as possible, including details that should be understandable. It probably is important to the participants that their involvement in the research study will not complicate their everyday life. In my studies, I had to be aware of the fact that it was demanding and tiring for the parents to have a child with pain. Talking to an interviewer about their children's pain or their own problems in this situation could also seem difficult and prevent participation. Trust in the healthcare system is thought to be an advantage when it comes to recruitment (176,177). All parents of children and adolescents with FGIDs who had a consultation with a pediatrician on Drammen hospital during the actual period were presented to the study. Twenty parents accepted initially, six withdraw. We could not ask why, and I did not know anything about them. They all knew that it gave no advantage to accept to be interviewed. As written above, there was a gender overweighting of females. I did not ask for the participants' age or education in Study I and II. Some characteristics is written in Section 7.1.1.I had no parents from Asia or East Europe in the study even though there are about 50 000 foreign inhabitants in the hospital region. It is impossible to say much about the sample. They were all parents of children with FGIDs and did represent these parents as a group.

Several of the participants in Studies I-III had an altruistic view of their participation; "If this can help other persons in the same situation, I'm willing to participate." In altruism, there is a concern for the well-being of others, with an obligation to care for others and without receiving (or even expectations of receiving) anything in return (180,181). Many of the GPs stated that they thought the study was interesting and they participated because if their experiences could make any change for these patients and also their colleagues' work, it was worth giving time. The fact that I also had been a GP for many years probably made more GPs accept the interview invitation.

9.1.7 Interview guide

The qualitative research interview was our "data collection tool" (182).
The interview guide was the basis of the research study. The guide consisted of preformulated questions and gave structure to the interview. In addition, there were unprepared follow-up questions that collected more unknown information from the participants (183). Because my interview guides had open-ended questions, it varied what the focus in the answers was. Nevertheless, the standard questions in the interview guide made the conversation structured. The combination of the preformulated questions and the follow-up questions led to a relaxed interview atmosphere with a formal setting as well as a looser conversation. Tjora calls it "asymmetry in expected formality" (100). The researchers' interest in knowing more about the subject becomes a driving force in the interview. Asking the participants further about the given information brought out interesting aspects and details from their FGIDs history. This was of course easiest in the interviews with the parents and adolescents, however, some of the youngest children also were willing to tell.
Our interview guides contained 9–14 questions. The interview guides in the second and third studies (follow-up interviews with parents and interviews with their children/adolescents) were built on the first interview guide to obtain further information about the situation explored earlier. In the fourth study, we wanted to hear what the GPs thought about the situation. The number of questions could have been increased, but the interview guide was thought of as a frame for the interview. Follow-up questions were asked in addition to the open-ended questions. Open-ended questions often give detailed and full answers and could make it more challenging for the researcher to extract similar themes and codes (128,184,185).
There could also have been fewer main questions, however, that could have made it more difficult to control the interviews. The interview guide was discussed with experienced colleagues who had worked for several years as GPs or pediatricians. After piloting two to three interviews, I discussed the questions again with the same colleagues (165). Especially the way of asking was discussed, how to explore to get the "best" answers, the most

interesting and thorough answers. It was important that the participants understood the questions (128). I kept all questions in the interview guides and added no new main questions. Interviewing children meant it was important that they understood the questions and that the questions were not too “scary” to answer. The children were asked if they understood, and if they felt something was unclear, I then tried to explain. This did not seem to be a problem during my interviews (discussed in Section 9.1.2.ii).

9.1.8 Technical issues—audiotaping of the interview

In research, as in many other disciplines in the last decades, there has been increasing use of technical aids. In qualitative research, the “method” has developed through the new technical equipment. A requirement in research is that there is informed consent in advance about the use of recording and the right to stop it or have it deleted after the interview has been completed. In my research, audiotaping was used in all the interviews. The participants were given written as well as oral information about audiotaping of the interview, all accepted this. This technical equipment made it easier for me to concentrate on the quality of the conversation and the follow-up questions with the participants during the interviews (100,137). The preparation for the high technical quality of the tape-recording in advance of the interviews was important. Placement of the recorder, batteries of high quality and avoidance of background noise had to be under control before starting the interviews (136). The reproduction of the participants’ linguistic expression and interaction is the main source in qualitative research and therefore crucial to have as correct as possible (137).

A weakness of audio recording in research is the loss of body language, nonverbal behaviors and situations in the environment during the interview. Field notes can help recapitulation of these factors afterward (186). I did not make notes during the interviews because I wanted to focus on the participants. However, after finishing the interviews, I made some notes for myself to remember each participant and the situation in each interview. These notes helped me recover other impressions from the interviews/participants than the verbal expressions.

I experienced twice that the participants restricted the information during the audio recording but wanted to elaborate on the answers to the research questions after the end of the recording, in a form of personal confidentiality. That could be because the participant experienced this as too sensitive material to be referred to in the research text or because they wanted some personal advice from a professional. As mentioned earlier, I twice gave some general advice after the recorder was turned off. I considered this to be correct then, to bring some comfort in a difficult parental situation (see Section 9.1.4). The question is can the material that emerges after the recorder is switched off be used in the research? In my opinion, this should be agreed upon with the participant in advance and could also be mentioned in the information letter. However, in interview situations with sad and desperate parents or children/adolescents, I suppose researchers will be emotionally affected, which might influence what is included in the research material. Tjora states that it is unfortunate to compromise on the interview and that a solution could be that only informants who approve audio recordings through the whole conversation should be included (100).

9.1.9 Transcribing the data

The transcription of the information in the interviews is essential. Transcription is the first step in the data analysis. Because transcription should be done with accuracy, it is a time-consuming process. Sutton states that it can take an experienced researcher/transcriber 8 hours to transcribe one 45-minute audio-recorded interview, a process that will generate 20–30 pages of written dialogue (186). Transcription is a technical procedure; however, it is more than that. Deciding what from the audiotaped interview should be included and how is a difficult and important task. In my studies, I interviewed and transcribed all interviews myself. Transcription was done the same day as the interview had taken place. This was experienced as an advantage; the interview was fresh and many visual and verbal details were remembered. It was possible to make some more field notes after the transcription to remind me of further details when I later should start writing. Because one person did all this "practical work," all interviews also got the same assumptions and perceptions of nonverbal factors. Nonverbal communication such as tone and strength of the voice, speed and pauses in the conversation together with other aspects of body language is a part of the interpretation of the interview. It is impossible to reproduce all details of human interaction in the script. However, it is important that all interviews are considered equally (186,187). In my opinion, the fact that the same person has done the transcription in all four studies would provide the most similar conditions throughout research work.

9.2. Data analyses

9.2.1 The choice of data analysis method

In qualitative research, there are different methods for data analysis (188–193). The choice of method depends on the study's purpose, aims, questions and objectives, type of data, size of raw material, etc. (188-193).

Malterud states that decontextualization allows us to lift out parts of the material and take a closer look at it together with other elements of the material that say something about the same thing. In the contextualization, we must ensure that the answers we have read from the decontextualized material still correspond with the contexts in which they were extracted. (99,105,149).

In Scandinavian health research, two methods are often used: Grounded theory (Glaser & Strauss 1967, Strauss &Corbin 1998) and Phenomenological analysis (inspired by Giorgi 1985), modified(Malterud 2003) as systematic text condensation (99,149,194–197).

Grounded theory has the intention to create new theory/theories. The method is useful when the research subject is new, or when limited research exists about the theme. The aim of my study was not to create new theories. Research has been done on this topic by other researchers. We wanted to learn more about the experiences of these young patients with FGIDs as well as their parents' and the GPs' experiences with FGIDs (197).

Phenomenology is the study of human beings' lived experience of the world. The researcher can through this procedure build a more generalized meaning of the experienced situation (198,199).

An Interpretive phenomenological analysis has its theoretical origins in phenomenology and hermeneutics. The participants make sense of and are experts on their own experiences, the researcher analyses and explains the complexity of their experiences (200–202).

A Thematic analysis means identifying patterns of meanings (themes) in a data set then analyzing and interpreting them. The themes are used to address the research or to say something about an issue. The Thematic analysis could seem to have some equalities to (qualitative) content analysis, however, there are some differences in the analysis and presentation of data. This method is used in just qualitative research and most often make analysis of interviews, different from content analysis which also can use visual images (videos, pictures) and can be used in quantitative studies (203–206).

Discourse analysis is to study communication and how language, such as communication and speech, achieves effects in specific contexts (207,208).

Systematic text condensation is a descriptive and explorative method for thematic cross-case analysis of different types of qualitative data, such as interview studies and observational studies. The method is inspired by phenomenology. It is modified by Malterud. The method is useful where much data material is to be analyzed, however, it is a time-consuming method and therefore demanding for the researcher (196).

Qualitative content analysis is about interpreting the meaning of different types of content (189). It systematizes selected text quotes, images as pictures and videos or other relevant documented sources to highlight specific issues. In content analysis, the choice of unit of analysis is essential. Units of analysis can be a person, a program, a clinic, observations, interviews, etc. (189). Graneheim and Lundman suggest whole interviews as the unit of analysis, which suited my studies (91).

Studies with much material to be analyzed often also use qualitative content analysis. I chose this method based on Graneheim and Lundman's qualitative content analysis (91). I wanted to clarify the parents', patients' and GPs' views on FGIDs. Content analysis seemed to me to be a method that made that possible. I also had much research material. The way of reducing the material and at the same time keeping the essential content was important. This content analysis describes manifest and latent content in the text. The manifest content is what is said in the text (the meaning units), the latent content is what the text "is talking about" (themes). The researcher interprets the underlying, latent, meaning in the text. However, the text can mean different things to different persons and subjective interpretations will always play a part (91). I have, during all these four studies used the manifest as well as the latent analysis. Understanding what the participants really felt and meant to say, I think was essential to be able to analyze their problems**.** I chose the same analysis method in all four studies. This will, in my opinion, lead to equal conditions and make it easier to compare and analyze the results.

9.2.2 Qualitative content analysis—step by step

Step 1: General impression and Preliminary themes. The beginning of the analytic process is about getting to know the research material. Interviewing all participants, myself, and making the transcriptions later the same day, was a benefit for me in this work. I did not make field notes during the interviews; however, after finishing the interviews I made some notes to remember the respondent and the situation. I listened to the transcripts, wrote and listened again. Through the transcription and later after reading each transcript several times I tried first to find out what the participants wanted to convey concerning the problems. The co-author(s) went through the same process him-/herself. At this stage, I tried not to use my interpretations because we were aware of the researcher's possible influence on the research and the research results. I looked for an overall picture and if there was content that later could lead to meaning units. There were between 3 and 10 pages of written text for each interview.

Step 2: Meaning units. Graneheim and Lundman describe a meaning unit as a "combination of words, sentences or statements that relate to the same meaning."

The text was systematized by finding and bringing together topics in the interviews that had something in common (unit of analysis). I marked the meaning units with different colors in the transcribed text. Meaningful units were then extracted from the text.

Example of a meaning unit: "It is extremely sad and frustrating. If there had been a diagnosis, it could have led to treatment."

Step 3: Condensation. The meaning units were condensed. Graneheim and Lundman state that the expression "condensed" is used to mark that the text is decreased (in size) however, "still preserving the core." It is important here not to lose the meaning which came from the empirical material. The condensed meaning units were written on a sheet of paper with their own color. It then was easier to distinguish them from each other and easier to obtain an overview. They were then put in different groups sorted by colors.

Step 4: The meaning units were abstracted and coded. Graneheim and Lundman state that abstraction is the expression for "description and interpretation on a higher logical level." The other author(s) and I asked ourselves "what this really was about" concerning the condensed meaning units. A group of meaning units were then assigned to a code.

The meaning unit above was coded to: Diagnosis and treatment.

I also marked from which interview the meaning units came.

Step 5: Similarities and differences among the codes were used to compare and shorten the codes to sub-categories and categories. The co-author(s) and I discussed the interpretations and analysis to achieve a common understanding. We discussed disagreement until we came to a solution for sorting the codes.

Themes were formulated out of the underlying meaning ("the latent content").

Example of a theme: Desire for a specific diagnosis.

According to Graneheim and Lundman, the establishment of categories is the core activity in qualitative content analysis. To abstract the subject to a theme is not necessarily required. The theme should gather the meaning of the latent content of the categories that have emerged in the analysis.

No software tool was used for the analyses.

Figure 1: Illustration of qualitative content analysis

Meaning unit	Condensed meaning unit Reduces text	Code	Sub-category	Category	Theme
It is extremely sad and frustrating. If there had been a diagnosis, it could have led to treatment.	Having a diagnosis could have led to treatment	Diagnosis and treatment	Asking for diagnosis and treatment	Parents' desire for diagnosis and treatment	Desire for a specific diagnosis and treatment

9.3. Critical reflection on the research process

9.3.1 Validity

There has been an ongoing debate in the research milieu on how to establish a yardstick for quality and trustworthiness in qualitative research results in medical health care (101,209). I choose to use the terms validity and reliability to assess the quality of the research (209,210). Validity refers to the truthfulness and credibility of the qualitative research results. High validity is secured when the research is grounded in other relevant studies and has a professional attitude (100).

Validity can be classified as internal validity and external validity. Internal validity refers to the structure and conduct of the study and if the results are valid for the examined samples and phenomenon. The sampling, the research procedure, the method, data analysis, etc. are crucial factors (211).

The researcher's ability and suitability as well as the conduct of the interviews, the transcription and the documentation of data affects the produced data (212) (see Section 9.1.4, 9.1.7-9.1.9). Internal validity is a prerequisite for external validity.

External validity refers to what extent the results can be transferred from this specific study to a wider population or situations (209,213). A professional attitude of the research and grounding in other relevant studies would secure this validity (100).

It must, though, be remembered that in qualitative as in quantitative research, the “one and only” truth does not exist (101,209,213).

I have described and discussed the interview, the interview guide, the sample/recruitment, the technical equipment, the role of the interviewer, reflexivity, the choice of research method and data analysis in previous Sections (9.1- 9.2).

My studies were conducted in a limited geographical area in southern Norway. Even if the health political plan states that there ought to be equal examination/treatment rights all over the country, the transferability of the results in all the studies might be affected by the limited research area. The fact that it could be more complicated to visit the GPs and the hospitals in some northern and western regions of Norway (transport, distance, roads, weather) could affect the external validity (214). The patients’ (parents’) threshold for seeing the GP, the GPs’ treatment procedures of young FGIDs patients as well as their threshold for referral to a hospital might also vary (214). No participants with families originating from Asia and Africa were included, which also makes it difficult to say if the results are transferable to integrated citizens from these continents. In Studies I, II and IV, where the participants were openly recruited, there was a predominance of female study subjects (discussed in Section 9.1.6). This could mean that there is a lack of external validity. However, my aim was not to generalize but to bring up experiences with FGIDs.

Kvale and Brinkman discuss communicative validity and pragmatic validity (101). The quality of the communicative validity is tried out in dialogue with the research society (100,101). Communicative validity is also about readability. The research results must be expressed so that other people can understand them. The communicative validity is low if the research results are not understood by others (100,101,215). The present study has been discussed with co-authors and other experienced colleagues, the study ideas and order of the interview studies as well as the interview guide, the data collection, the data analysis, the pilots and the transcriptions. As to the language and the expression of the themes, I have tried to balance between an understandable language also for nonmedical readers without losing the medical academic language. The thorough peer review process in the journals that published my studies also is a sort of guarantee for communicative validity. The pragmatic validity is tested in the question “Does the research lead to changes or improvements?” (100,101). Pragmatic validity is linked up to relevance and if and how knowledge is used

(100,101,215). The pragmatic validity will depend on the way of publication and distribution of the study results. Both patients and parents as well as GPs and other specialists like pediatricians hopefully will obtain some new information from this study.

9.3.2 Reliability

Reliability involves the question of whether the results could be reproduced at other times and by other researchers (101,205). Reliability can be defined as: Internal reliability: The extent to which other researchers can use the conceptual apparatus for the analysis of data in the same way as the original researcher. External reliability: The degree to which different researchers will discover the same phenomenon, generate the same concepts in the current and similar situations (100,101,216). Consistency and accuracy in all practical matters concerning the research would secure reliability.

In qualitative research, the researcher herself represents a part of the instrument, which impacts the reliability. Through describing the choices of strategies completed in the research procedure in the study, the reliability is improved. The interviews, the transcription, data analysis and the presentation of the results are processes that should be highlighted (93,101,195,215,217).

Through all four studies, I have tried to follow the “research description” concerning reliability. This is all described in Sections 9.1–9.2. If another interviewer had presented the same interview guide to the participants, I think that would have affected the answers and maybe the interpretations. It might though also have increased the reliability if there had been two or more interviewers. This was, however, not possible in these studies. By describing the research process in detail, I have tried to secure reliability. However, I think using a qualitative research model makes it more difficult to secure high reliability than using a quantitative research model.

9.3.3 Checklists—evaluation forms

To improve the transparency of the qualitative health research checklists, a standard set of items for reporting was made. Two often used checklists are: COREQ: Consolidated criteria for reporting qualitative research, a 32-item checklist from 2007 (218) and SRQR: The standards for reporting qualitative research, a 21-item reporting from 2014 (219). The checklists are meant to improve the quality of the qualitative research. The researcher will be helped through the checklists in the describing/reporting of different parts of the study, such as the study design, the findings, analysis and interpretations. This will raise the quality of the research through increased transparency described in Sections 9.3.1–9.3.2 (218).

I used COREQ in all four studies. It helped me to remember different items, especially when writing the articles. SRQR is also reported to clear the standards of reporting qualitative research which will help authors, editors, reviewers and readers with evaluating a manuscript (219). The checklists also have had some negative comments such as the fact that these checklists could make qualitative research more rigid and structured, more like quantitative studies. The critics of the checklists state that qualitative research needs creativity and freedom to write, which perhaps could be reduced by such control routines (220,221).

9.4. Discussion of main findings

Through four studies, I have explored children and adolescents with FGIDs. The parents in my study meant that their children's and adolescents' FGIDs mainly had a physiological cause, although some parents were aware of the possibility that psychosocial conditions could affect the situation.

A diagnosis and an explanation of the diagnosis were important for the parents. The desire for information and "someone to talk to" about the symptoms was essential, both for patients and parents.

The GPs were concerned that these children and adolescents should not go through repeated complicated examinations.

These patients "belonged to" the GPs in primary health care and should not be referred to hospital/specialists. However, about 568 children and adolescents with FGIDs were referred to VVHF in one year (in 2015).

9.4.1 Strengths and limitations

The researcher is a GP and a child-and-adolescent psychiatrist herself. I think that was an advantage in all four studies. I am used to talking to adolescents as well as children and parents in my work. When talking to and interviewing young patients, especially children, it is necessary to understand their way of reflecting and expressing themselves. When interviewing the GPs, I also think my education and work was an advantage, however, it could be that a nonmedically educated interviewer would have obtained different answers.

The changing conditions for conducting interviews due to the pandemic meant that data collection for Studies III and IV had to be done by video (Study III) and telephone (Study IV) instead of by personal interviews. I then lost much of the nonverbal language that I think could be a part of the interpretation in addition to the verbal answers. The two interview studies with the parents in 2016 and 2019 were, however, both personal interviews. I interviewed participants until I thought I found data saturation, however, some new information could always have come up in the next interview. When the children and adolescents were interviewed (in 2020) some time had passed since they were in hospital (1–4 years). Some of them then had recovered from the FGIDs. That could have reduced their memories of the symptoms. Most of the children and adolescents though gave detailed information of their symptoms and their experiences with FGIDs.

If the studies had included participants from the whole country, it might have influenced the answers. It is a fact that the geographical conditions in Norway, especially during the winter, influence the possibilities to visit GPs and hospitals (214).

There was a predominance of female participants in the studies. Having a more equal distribution of gender might have given changes in the answers.

In Study I, there were three persons in the research team, in Studies II–IV the team consisted of two researchers. Having had more persons in the research team could have expanded the discussion.

As far as I have found out, my study is the only study with an interview of parents of children and adolescents (222), a follow-up interview after three years (223) and a subsequent interview study with their children and adolescents about their FGIDs (224). At last, GPs from the same health region have been interviewed about the same topic (children and adolescents with FGIDs) (225).

9.4.2. Children/adolescents and the Norwegian GP scheme

For children and adolescents with FGIDs, a “vicious circle” with repeated examinations and many doctor assessments should be prevented. This task will probably be more difficult for a GP if the patient and their families are not well known in the practice. The GP scheme is meant to ensure that the children and their families have the same GP for years. Knowing the family history and their health problems were factors the GPs in my studies underlined as important to be able to give good advice and treatment to these patients and their parents. The GPs reported being confident in labeling chronic abdominal pain as FGIDs.

There ought to be a physical examination with blood tests, urine and stool samples to exclude serious disease, but the scope of these tests should be limited. The physical examination is also seen as a part of the important alliance building between patient, parents and GP. This establishment of empathy early in the patient–physician relationship is described as essential in the treatment of FGIDs (64).

The presentation to the patients and their parents of the fact that these symptoms are common and rarely associated with a serious disease should be prioritized at an early stage in the treatment process (64,68,69). The repetitive visits by the GPs could otherwise end up with intensive examinations together with experimental treatments with diverse diets or other restrictions to the child's life (226). The GPs in my study thought that children and adolescents with FGIDs "belonged" in general practice. Other researchers also underline the fact that FGIDs should be managed in general practice especially because of the family factors and the multifactorial onset (226). Brett et al. emphasize the importance of the holistic approach to these patients and that the GPs are best suited for this way of practicing medicine (73).

The time factor for GPs' consultation is different in Norway compared with GB (GB: about 10 minutes, average 9.2 minutes consultation (227). Norway: average 15 minutes (228)). I think that having consultations without time stress is important for this patient group. One can, however, argue that the consultation time is not essential when it comes to a valuable conversation. A short conversation between the GP and the child/adolescent alone could be helpful. The child/adolescent's participation in decision-making concerning their treatment should be considered. However, the age of the child, maturity and acquaintance of the child are crucial (229). Age-appropriate question methods should be used. It is, therefore, important for GPs to master interview strategies that match children's developmental levels (122,123).

9.4.3 Cultural views on FGIDs

The only exclusion criterion for participating in the study was that parents did not understand and speak Norwegian. There was no interpreter connected to the study. Four of the parents came from foreign countries (Sweden, Iceland, Russia, US). They had lived in Norway for several years, spoke and understood Norwegian well and were used to the Norwegian healthcare system. These parents' origin might influence some of the answers because attitudes to diseases with psychosomatic symptoms may differ. The parents themselves answered that waiting time for an appointment and the use of private specialists could differ in their country compared with Norway, but otherwise, they did not think there were any important differences.

The prevalence of FGIDs is influenced by different factors, such as female gender, psychological disorders, stress and traumatic life events (230).

Concerning the prevalence of FGIDs in Asia, a study from 2021 states that little is known about FGIDs from the South East Asian region. This study however reports that there are similar prevalence rates of infants' FGIDs in the South East Asian region to those published in the literature except for lower infant colic and functional constipation (231).

The socioeconomic status and nonculture social variables concerning pain are known to be complicated and influence the pain situation (232).

The European Network on Psychosomatic Medicine states that as "we gain a better understanding of the mechanisms involved in these complex diseases, especially on the psychosocial influences, we should also develop strategies to promote this knowledge in each and every country, thus allowing its implementation into their medical practice" (233).

Cultural factors also seem to be important both to physician–patient relations, to the family systems as well as to the biological aspect (230,234).

There are differences in symptom presentation and disease subtyping both in functional dyspepsia as well as in IBS in the world, as in Asia compared with the Western countries. Cultural perception of the symptoms or cultural dietary practice is thought of as a reason for this (9). Some cultures' views of health and health care are reported to be culturally influenced. In some Asian cultures, they do not talk about their own pain, and they communicate differently with Asians than with non-Asians. The presentation of mental problems could, for example, be presented through pain. This could complicate several aspects concerning acute as well as chronic pain and disorders (235).

The importance of adapting the introduction of the biopsychosocial model in treating functional symptoms, including FGIDs, to other cultures is stated in Sharma et al.'s study (236).

As to my study, there are more than 50 000 foreign inhabitants in the hospital's catchment area where my studies was performed, many from Asia. However, I did not have any Asians in the studies.

9.4.4 FGIDs in children and adolescents, just a somatic symptom?

Fiertag et al.'s study states that children and adolescents with FGIDs or other somatic symptoms/disorders often contact their GP or a pediatrician (237). Because the symptoms are perceived as physical and the families think there are no or just a few psychological causes of pain, psychiatrists or psychologists are not consulted. In my first two studies (I and II), the parents had the opinion that the children's and adolescents' FGIDs had physical causes even if all the examinations in the hospital and at the GPs had been normal. Some of the parents opened up for thoughts that trouble with school and/or friends could influence the symptoms, however, they considered this just as an additional factor. Some of the parents also wanted to continue the examinations of the child/adolescent. Only a few of the parents thought it was important for the child to meet a psychologist or a psychiatrist to talk about the FGIDs. In my view, the adolescents seemed to have a more comprehensive view than their parents on the causes of their symptoms.

In my studies, the parents and the children/adolescents had several meetings with the GPs as well as with the specialists in the hospital, and still they thought the gastrointestinal symptoms mainly had a physical cause. Does this mean that the parents did not trust the specialists in the hospital and the GPs?

A study from Finland states that parents, as well as teachers, often did not realize that their child had psychosomatic problems. Somatic symptoms in children are shown to be linked to hyperactivity, behavior symptoms and depression (238). As the GPs in my study stated, it is important to have a conversation with the child/adolescent together with the parents but also a small conversation alone, if possible. A direct question about the somatic and mental status may reveal symptoms not reported by the parents. I would propose asking children more about their mental health status when they consult the GPs for different types of symptoms (238). We do not know if the parents in our study had overlooked or underreported any symptoms or complaints with their children/adolescents. As reported in my studies, it seemed as if parents, teachers as well as children/adolescents were not aware of the correlation between somatic symptoms and psychological stress. This corresponds to what was reported in other studies (239,240). In my opinion, this may be one of the main problems with this patient group and important to address to improve the life quality of these patients. GPs and pediatricians must focus on the biopsychosocial model and plan their treatment accordingly. Thapar et al. stated the importance of not focusing on just biological causes of these disorders (241). That is seen as a disservice to this patient group as well as to all diseases and disorders

(241). Another important fact is that also parents' distress and behaviors have an impact on a child's pain experience, whether in the context of acute (242,243) or chronic pain (244).

9.4.5 The need for a diagnosis and contact with a physician

Diagnostic uncertainty has been defined as the clinician's "subjective perception of an inability to provide an accurate explanation of the patient's health problem" (245). There could be several reasons for such a diagnostic uncertainty from the physician's view as well as from the patients' and parents' views. In my studies, the patients' and the parents' needs and desire for a diagnosis were the main topics. A study from Switzerland reported that the parents of adolescents with unexplained pain wished the symptoms were of serious pathology instead of having no explanation (246). I think this could explain the requirement and importance of an understandable and acceptable diagnosis.

Disorders with a diffuse quality of symptoms, symptoms that change in character and have a complex symptom history, could be difficult for the physician to diagnose or to explain to the patients and the parents (247–251). GPs' short consultations (15 minutes in Norway) and also limited possibilities for testing could complicate the possibility of informing, explaining and diagnosing.

Diagnostic uncertainty could also refer to the patients' and parents' perception of the diagnosis (252). Parents' and also patients' trust in the GPs is an important factor in accepting the given explanation or diagnosis (253–255). As mentioned above, the way of communicating the diagnosis is important. I think showing empathy and understanding for the patient's and the family's difficult situation is crucial. However, a clear and concrete explanation is necessary for the treatment of FGIDs. Trivić and Hojsak state that diagnosing FGIDs in the first physician visit significantly increases the possibility for symptom reduction (256).

This fact makes it even more important to improve the information and the way of informing the patients and parents about FGIDs.

Parents, children and adolescents in my studies stated a strong desire for a diagnosis. As long as the child and adolescent had no diagnosis and FGIDs affected their lives and thereby the parents and the family, the parents reported that they had to look for their own solutions. Some of the parents demanded further examinations of the child such as ultrasound or CT scan to be quite sure the symptoms were not caused by cancer. In my studies, great worries for serious disease seemed to continue because the child/adolescent did not recover from FGIDs and did not have an acceptable diagnosis (68,69,257).

In the study by Noel et al., 40% of parents of youth with chronic pain still were unsure and searching for a diagnosis after having been to a special chronic pain clinic where they received feedback and education about the adolescents' diagnosis (258). Tanna et al. reported that 37% of parents and 48% of children thought that something else was going on with the child's pain that the physicians had not found out yet (259). Neville et al. stated the parents reported that they thought the clinicians did not understand the children's pain, which reduced the trust in the clinicians (260).

If the parents and patient had received an understandable medical explanation of FGIDs that they could accept as truthful, this would in my view reduce the claims for further examinations. This understanding could make them more familiar with the advice or treatment for FGIDs. It would probably be easier to cooperate on the treatment. However, to give a good explanation about the cause of the symptoms also requires good communication between patient, parents and the GP. Palermo and Baeyer state that "Communicating with parents in a sensitive manner is essential to facilitate understanding and acceptance of a biopsychosocial perspective on chronic pain" (261). One of the GPs' tasks in this situation would be to communicate the information about the biopsychosocial model and further treatment.

Many of the parents in my studies asked for "a professional" to discuss with. The children and adolescents described how fear of serious diseases such as cancer disabled their lives. Some of the adolescents stayed home from school for weeks. In addition, some of them did not know who to talk to about this fear. The fear of serious disease needs to be taken seriously (68,69). This fear often triggers the desire for further examination and thereby increases stress, which in turn will maintain or increase the symptoms in FGIDs. The children and adolescents get more isolated and increasingly worried about their symptoms and situation. It is important to break up this circle of symptoms, worries and isolation. Some of the adolescents in my study reported having had one specific conversation with a physician who informed about and explained the pain mechanism. This consultation stopped the negative process and the adolescents' lives could gradually be normalized. They seemed surprised over the effect of the information and explanation of the symptoms because they had been to different investigations and consultations before without any effect on the symptoms.

Patients’ and parents’ understanding and so their ability to control stress and worries thus are essential in the treatment of FGIDs (68–70).

The GPs in my study stated that one of their main tasks in treating children and adolescents with FGIDs is to give information and psychoeducation to parents and patients. Nevertheless, the parents said that they missed a physician to discuss with and that they did not get enough information. It seems to me that there are two perceptions of needs and treatment. The patients and the parents seemed to call for something that the GPs thought they had given them. It might improve the situation for the families and the patients with FGIDs if it could be possible to structure these consultations as a fixed communication–information program, to secure that the information is understood and accepted.

It could be that the way of giving information—the communication—is essential for the understanding of the symptoms and the treatment for these patients as well as their parents. In the education of pediatricians and other healthcare providers, it is emphasized how to communicate with parents and patients about children’s and adolescents’ chronic or acute pain (55,262–264).

Koechlin et al. state that one of the most important parts of the treatment of pediatric chronic pain is to educate parents and patients about pain. This study suggests that education should be a part of a comprehensive treatment plan. To communicate better with these pediatric chronic pain patients, their study underlines: “1) An emotionally warm and empathic communication style is needed. 2) The patient’s expectations about the treatment need to be taken into account. 3) Understandable and plausible information that allows for a reconceptualization of chronic pain, the use of an evidence-based model such as the biopsychosocial model of chronic pain and a delivery mode that includes metaphors, drawings, and layman terms. 4) Parents need to be involved in the process of understanding their child’s pain better” (55).

As I have experienced through my conversations with the children, the adolescents, the parents and the GPs, the physicians give these patients a diagnosis: FGIDs. Often, however, this diagnosis is not understood or accepted by the parents. Through the parents’ conviction, the adolescents and perhaps also the children come to the same conclusion. Because the diagnosis given by the GPs or pediatricians does not seem to satisfy the parents, the treatment that is prescribed also does not fit their expectations. The result could be that the parents and patients feel that they have not received any diagnosis, and therefore need to continue the investigation.

The age and developmental status of the child and adolescent are crucial for when being able to take their own decisions about their FGIDs, however, their parents probably will be involved in their treatment for a long time still. Several studies have focused on parents' behavior and distress concerning the child's symptoms, the treatment and also how these reactions may influence the children and adolescents (242–244,265–267).

Through interviewing parents and these young patients as well as in my clinical work, I have seen the importance of having the parents' confidence in the treatment. I think it would be nearly impossible to have the children's and adolescents' acceptance of the diagnosis and treatment if the parents are of another opinion. This also applies to the understanding and explanation of the biopsychosocial model as essential in the treatment of children and adolescents with FGIDs (61-63,268,269).

9.4.6 Referral of children and adolescents with FGIDs to secondary health care

The study was started at the Child and Adolescent Department at Drammen hospital. When I worked there, I met these patients, children and adolescents with FGIDs and their parents. The hospital received 568 referrals of children and adolescents with abdominal pain in one year. When interviewing the GPs, they claimed that these patients "belonged" in primary health care and that they would rather not refer them to hospital. Their reasons for referral were the patient's loss of physical or psychological functions or other alarming or "red flag" symptoms, including a long-term pain situation. However, they stated that a reason also could be that the parents demanded to see a specialist or that the GP needed support from a colleague. This was stated by more experienced as well as less experienced physicians. As a rule, the patient returned to primary health care because the specialists did not find any specific disease. These referrals to specialists did not seem to be beneficial to anybody. The children and adolescents continued to have their FGIDs, the parents often were not satisfied without a somatic diagnosis and an explanation, the absence from school often continued, the families' lives still were affected by the situation. And the GPs had to cope with the young patient with FGIDs without any prescribed treatment or solution.

The FGIDs were seen in a biopsychosocial context by the GPs in the study. Implementation of a treatment built on the biopsychosocial model seems to me to be important. A trusting relationship between the doctor and the family was highlighted by the GPs as essential for the patients and parents to follow their advice (225). They also emphasized showing empathy and support during difficult times and showing that they took the FGIDs seriously. Training of the physicians in the model but also a scheme that enables a systematic implementation of the treatment seems to be crucial for these patients and to strengthen the GPs' treatment. This could consist of a certain "education program" for the patient and the parents with one appointment each week. Because Norwegian GPs have very busy days, this could be a challenge. However, these patients return to the GPs when the symptoms increase, so they will occupy the GPs' time anyway.

9.4.7 Consequences of FGIDs

The parents often reported that in a way, the child's FGIDs gave the family a joint project in how to manage the symptoms. To some families, the FGIDs became a sort of glue in the family. Some few parents thought it was important to teach the child and adolescent that somatic sensations were not a dangerous disease, and that sensations as joy and anxiety often could be felt in the body, especially the abdomen. The parents as well as the children and adolescents themselves expressed a wish to have a GP or another physician to communicate with about FGIDs, how to live with the symptoms and how to be a parent during the periods of pain.

All the children, even the youngest, and the adolescents seemed to express more concerns than their parents about the fact that the FGIDs were related to nonphysiological factors or even to mental stress. The parents' fear for physical disease and especially serious disease seemed to cover their recognition of the children's worries that gave them FGIDs or at least increased the symptoms. This appears through all the interviews to various degrees.

The adolescents clearly expressed sadness and depression for not being able to take part in the "youth society" such as school and friends because of FGIDs. They felt excluded from the world that they should belong to. I did not find that their parents were properly aware of this. I think the parents did their best to help their children and adolescents, but I do not think they saw the range of the problems. Children and adolescents have little life experience, and the understanding of the difficulties did not appear clear to them. Both patients and parents looked for solutions based on their own assumptions.

Children and adolescent do not always report their symptoms, which of course makes it difficult for their parents to know when and if their child or adolescent has pain (270,271).

It was also reported that parents did not seem to have the required information about the body functions such as the bowel and bowel habits, especially in adolescence (272,273). These facts I think could complicate the understanding of the children's and adolescents' symptoms and also the reactions to the symptoms.

It is reported that pain could be difficult to recall later (274). Especially for children and also adolescents it could be difficult to recall periods of pain and the intensity of pain. Abdominal pain seemed to have a low frequency for recall in children (274). This also is an interesting fact in my view because the prevalence of pain and disorders, FGIDs included, is based on retrospective data of children's recall (274).

10. Ethical considerations

The Regional Committees for Medical and Health Research Ethics approved the studies I, II and III (reference no. 2015/1928, 2019/646, 2020/93964).

Study IV: The Regional Committees for Medical and Health Research Ethics informed that the study did not need their approval (reference 2020/184272). The Norwegian Center for Research approved the study (reference 2020/349340).

The studies have 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, children, adolescents and GPs.

Informed consent: The interview subjects gave written consent to participate. Even when only one of the parents was interviewed, both parents signed the declaration of consent. The children, adolescents, parents and GPs were informed about the studies through an information letter. Children 16 years or older provided written consent for their interview and for stating that their parent(s) could participate.

All participants were informed about the aims of the study, that they could withdraw from the study without an explanation, who performed the analysis and who had access to the data.

Confidentiality: Before starting the interviews with parents, children, adolescents and GPs, they were informed that their confidentiality was ensured; the collection of data would be anonymous, and soundtracks were deleted after transcription. In the transcription, the participants have numbers instead of names or called the mother of child #. The used quotes were of the type that could not lead back to a specific person. In the text, anonymizing information was used. I have been in contact with the parents three times, and I have not heard any complaints after the interviews. However, I cannot guarantee that no participants felt insecure or regretted the participation.

Consequences: The interviews dealt with sensitive information that could be difficult to talk about and evoke stressful emotions. I tried to be aware of this situation and to pay attention to the participants in a professional way. I was in contact with the parents three times, interviewed them twice. They all participated both times and gave positive feedback. Talking to the children and adolescents, I tried to be careful and considerate. However, the participants might have regretted being interviewed or sharing sensitive information with me as a researcher.

The researcher role: As debated in the text, there often will be an asymmetric balance in the interviewer–participant role. Sensitive and private information is shared with the interviewer by the participants. It is important that they feel a certain choice of what information they will share. When interviewing children and adolescents, I think this is even more important (275). It might also have happened that children had given serious information that I would have to bring further to the parents, their GP or to the Child Welfare Service (Barnevernstjenesten) (276). Problems like that must be thought of when dealing with young participants.

COVID-19: The pandemic in 2020–2021 forced restrictions on personal meetings. The original plan with face-to-face interviews had to be canceled. Studies III and IV, therefore, had to be completed with video interviews and telephone interviews (277).

11. Conclusions

Clinical experience, earlier research and also my studies have shown that many children and adolescents suffer from FGIDs, which strongly affects them as well as their families. Their physical and mental status are affected. It, therefore, is important to treat and prevent further symptoms. A treatment program should be based on general practice, but interdisciplinary treatment would probably be advantageous. Psychologists, nurses and physiotherapists with interests in psychosomatic treatment could be in the treatment team. The biopsychosocial model should be explained with words and illustrations to the patient as well as to the parents. Psychoeducation and information ought to be part of the program because understanding the treatment is essential. Cognitive behavioral therapy could be used. A few appointments could be with the patient and the parents separately. The main goal of the treatment is that the children and adolescents as well as their parents should return to normal life function with school, work, friends and other activities. Such a treatment program could be implemented in GPs' specialist programs as well as in their continuous education. Probably parts of such a program would be useful for treating other functional disorders.

12. Future perspectives

The study has shown that even if GPs think the children and adolescents with FGIDs belong in primary health care, the hospital often receives referrals of these patients. A structured treatment program as described in Section 11 should be created and tested out in general practice and evaluated. If it is found to be feasible and useful, it ought to be part of GPs' educational programs.

Why FGIDs are mainly perceived by parents as a potentially harmful physical disorder should be further explored. Opening the parents' eyes to a multifactorial cause and the biopsychosocial model could hopefully change their approach to the symptoms. The best way of explaining and informing the parents should be investigated. The serious consequences of FGIDs for children and adolescents would then hopefully be reduced.

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ERRATALISTE

Kandidat: Anne Brodwall

Avhandling: Children and adolescents with functional gastrointestinal disorders

Ref. 2022/6031

Side	Linje(med tekst)	Orginal tekst	Type rettelse	Korrigert tekst
6	5	Kjemperud	Cor	Kjemprud
13	6	568	cor	627
16	24	Linjeavstand mellom4 linjer IASP Revised Definition of Pain 2020	Celtf	Skal være samme linjeavstand som ellers i avhandlingen
17	Nederste 3 linjer. ICD-10 however, functional intestinal disorder unspesified	In ICD-10, however, functional intestinal disorder unspecified and unspecified functional disorders of the stomach are included.	Cor	In ICD-10, however, functional intestinal disorders unspecified and other specified functional intestinal disorders are included.

14. Appendix

Interview guide study I

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 father/mother/siblings 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 in the hospital last time you where there with your child?
9. Your child has been examined at the hospital. They did not find anything wrong. How did you feel about that?
10. How do you feel about the hospitals follow-up of the child's stomach pain when the tests were negative /normal?
11. Which country do you and your family come from?
12. Can you tell how your country traditionally treats pain; any difference to the Norwegian treatment?
13. What could make you more secure about your child's stomach pain?
14. Is there anything else that I should have asked you concerning your child's stomach pain?
15. How was it to be interviewed?

Interview guide study II

1. Considering your child’s/adolescents stomach pain, how is she/he doing now?
2. How has the last few years been for your child/adolescent concerning the stomach pain? For the family?
3. Has the child’s /adolescents stomach pain affected the family (parents/siblings)?
4. How has the stomach pain relief/worsening affected the family (parents/sibling)?
5. Has the child/adolescent been followed up by doctors the past 3 years?
6. Has your child/adolescent been followed up by others than doctors/hospital recently?
7. What do you think has made her better/worse today?
8. Is there anything else I should have asked you about (concerning the pain)?
9. How did you experience the interview?

Interview guide study III

1. Do you have abdominal pain these days?
2. Can you tell me about the last time you had abdominal pain?
1. Can you describe the pain? Has there been any change in the pain?
2. What do you do when you have abdominal pain?
3. At school? During the weekends? During your spare time? During your holidays?
4. Is there anything you can do to improve the abdominal pain?
5. Have you taken ‘painkillers’?
6. How do your father, mother and siblings react when you have abdominal pain?
7. How do you experience the situation at home when you have abdominal pain?
8. What do you think causes your abdominal pain?
9. Have your parents explained the abdominal pain to you?
10. What was it like to be in the hospital for examination?
11. Have you been to the GP?
10. Have you seen therapists other than the medical doctor? Alternative therapists?
11. What might make you feel secure about the abdominal pain?
12. Is there anything else I should have asked you about the abdominal pain?
13. How was it to be interviewed?

Interview guide study IV

1. How often do you see children or adolescents with long-term or chronic abdominal pain?
2. What do you do when a child or adolescent presents with chronic abdominal pain?
3. Do you have any thoughts about contributing factors or conditions that may provoke or increase abdominal pain?
4. Do you have any impressions about how the pain affects the child's family?
5. Do you refer any of these patients to hospital or a specialist? If yes, whom?
6. If a child or adolescent has been seen by a specialist and returns to you without a physical diagnosis, what do you do?
7. As a GP you have a busy day with 15–20-minute consultations; how is it possible to follow up with these patients?
8. What is your impression about what these patients and their families need?
9. Do you usually contact the patient's school about measures that could make the school day easier for the patient?
10. Do you know how these patients are doing over time?
11. Do you (as a GP) have any advice about following up with children and adolescents who have functional abdominal pain? What do you think may help them?
12. How do you experience the consultations with these patients and their parents?
13. Is there anything I should have asked you that has not been asked in the interview?
14. How was it being interviewed about these patients?

15. Paper I – IV

PAPER I

Open Access Research

BMJ Open

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

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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, audiotape recorded and transcribed. A descriptive content analysis was used to analyse the transcribed text.
Setting Parents of children referred from general practice located in urban and rural areas in two municipals in Norway.
Participants Fourteen 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 prompted their doctor to do further examinations. However, some parents knew that social factors could inflict pain and were concerned that their child was unable to distinguish sensations like anxiety and 'butterfly' tensions from physical pain. The parents and children needed professional guidance on how to manage the pain .
Conclusion The doctor's consultation should not end at the diagnosis of functional abdominal pain. Doctors may help these families further by focusing on pain management strategies.

Strengths and limitations of this study

- The individual interviews reveal that the whole family is affected when one child has chronic abdominal pain.
- Parents of children were interviewed when the children had just been discharged from hospital; this enabled recording the experiences before their memory had faded.
- The sample size was small, and only parents well-integrated into the society were 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 characterised 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 USA and Europe range from 0.3% to 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 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 learnt.[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, and 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 is expected to be given by the general practitioner (GP). Often the GP lacks support by specially trained healthcare personal like psychologists or nurses for these cases. This study examines different experiences reported by parents in handling RAP in one of their children. We want to know more about mother-child or child-parent relation to the pain, and 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 semistructured interview guide was developed (box 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 that 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.

Box 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 the 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 mid-sized Norwegian town that covers 440 000 inhabitants within the town and the 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: Inability to communicate in the Norwegian language. A dedicated nurse at the outpatient department recruited parents of children aged 5–15 years recently presenting with RAP.

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

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 categorised into subcategories and categories, form which the 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 whole 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 prioritising 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 recognised 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 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 felt they are responsible for helping their child without knowing what to do.

They felt they were to be blamed, which was a very hurting experience: '*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 wanting to consult a professional for both the child and the parents: '*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 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 RAP 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, because of the child's condition the whole family's focus was on 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 they wished to have professionals with whom they could discuss their perceived shortcomings in caretaking and to guide the child on ways to live with their painful condition.

How the pain rules the family

Some families went into a new mode of living during the 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 feel ashamed of not being able to 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 parents' 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 overinvolvement. 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 healthcare 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 the time and interest for discussing and excluding other diagnoses. Psychoeducation about the pain and strategies on how to handle the pain in daily life are also 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.

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PAPER II

BMJ Open

Understanding parents' experiences of disease course and influencing factors: a 3-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.

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, although 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.

Strengths and limitations of this study

- The main strength of the present study is that the complete cohort of parents who had been interviewed 3 years ago agreed to be interviewed again.
- Another strength is that the same researcher carried out all interviews on both occasions.
- The use of semistructured interviews enabled detailed information about the parents' experiences over the 3 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 disorder (FGID) 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 FGID, which is characterised 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, British paediatrician John Apley[2] published his pioneering research into children with abdominal pain, which was then called recurrent abdominal pain; this has now been replaced by FGID. Apley[2] found that 11% of British schoolchildren had FGID and stated: 'It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment'. He was the first to establish criteria to define FGID as a distinct syndrome.[3]

Complaints of chronic abdominal pain occur in 10%–19% of children, with prevalence highest in children aged 4–6 years and in early adolescence.[4] The prevalence rates of chronic abdominal pain among school-age children in the USA and Europe range from 0.3% to 19%.[5] In almost 90% of these children, no explanatory organic cause can be identified.[6] There are no significant differences in FGID related to sex, race or ethnic groups, except in functional constipation, which is significantly more prevalent in male compared with female patients.[7] There is overlap between parental and child FGID symptoms. Children with FGID report a lower quality of life compared with healthy children.[7]

The child's or adolescent's and their family's life quality is 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 aetiological 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 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 exclusion 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 3 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 FGID, but with no therapeutic responsibility. The interviewer was empathetic, although 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 min. A semistructural 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 transcripts were not returned to the participants for comments.

Data analysis

Qualitative content analysis was conducted based on the 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 subcategories. From the categories,

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?

Figure 1 Interview guide. GP, general practitioner.

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 were involved.

RESULTS

Participant and child information

In total, 15 parents of 14 children were interviewed: 9 mothers, 4 fathers and 1 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 3 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 to 17 years and from 8.8 to 15 years, respectively. The three children who still had pain were 9, 10 and 11.5 years old.

We identified three main themes:

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

Theme 1: family burden and frustration, and how school issues implied 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, and 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 2 months" (Interview 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 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 2).

Table 1 Current status of the children's abdominal pain

	Total (n)	Girls	Boys
Recovered	9	4	5
Still with symptoms	3	1	2
Unsure situation	2	2	0

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 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 4).

Some of the siblings' teachers had noticed 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 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 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 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 14).

Theme 2: the consequences of improvement

Nine of the 14 children (5 boys and 4 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 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 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 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 1).

Theme 3: desire for a diagnosis and for advice

Some of the parents emphasised 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 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 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 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 and so on) that affected the pain. Four of the children had talked to a child and adolescent psychologist, and another one parent 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 FGID 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, although 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[16], parents should be advised to reduce concerned responses to their child’s pain, focusing on distraction instead. Walker *et al*[17] 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. The goal of treatment thus will be return to normal activities, rather than removing pain. The parents in the current study wanted a closer cooperation with school and believed that it was a prerequisite to successful treatment. However, they emphasised 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 other studies.[18] The child’s possibility to a successful stepping forward into adult life also must be an aspect of the treatment.[18]

In families with more than one child, the parents’ 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 FGID have significantly higher mean levels of emotional and/or behavioural 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[21] wrote about the concept of ‘the child as the presenting symptom’. 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’ behaviour can be seen as operant factors that serve to either increase or decrease adaptive child behaviour.[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 both to exclude organic causes and to identify eventual positive indications of emotional problems.[24] Crushell *et al*[25] found that only 1 in 14 parents of children with ongoing pain believed that there was a psychological cause for their child's pain. 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, it is important to include psychological therapy such as cognitive–behavioural therapy in the treatment plan.[16] Psychological interventions for managing paediatric chronic pain have involved the parents in treatment using this approach, that is, teaching the parents techniques to increase adaptive child behaviours 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 *et al*[26] reported that parents' emotions, behaviours and health play a role in children's pain experiences.

The expression "grew out of the pain" was used by 6 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 (ie, 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 emphasise 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–behavioural therapy or other psychological interventions may help the families, and follow-up over time by a trusted physician is essential.

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Contributors 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.

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PAPER III

BMJ Open

Children's and adolescents' experiences with functional abdominal pain: a qualitative study in Norway

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ABSTRACT

Objective Functional gastrointestinal disorders (FGIDs) are common during childhood and adolescence. When a somatic diagnosis is excluded, the healthcare system often terminates contact with the patient. The aim of the present study was to learn more about children's and adolescents' experiences with, and reflections on, the causes of their abdominal pain and what could possibly help them.

Design The study has a qualitative design. Interviews with open questions were carried out by the first author. The conversations were audiotaped, transcribed and analysed by means of qualitative content analysis.

Setting Children and adolescents referred from general practitioners located in urban and rural regions in two municipals in Norway. In 2016 and 2019, we had interviewed these children's parents about their child's abdominal pain. In spring 2020, the children and adolescents were interviewed.

Participants Twelve children and adolescents aged 10–18 years with FGIDs.

Results Eight of the children and adolescents had recovered from their abdominal pain, while four still had symptoms. They felt frustrated by not having a diagnosis and by the lack of available treatment. Some who had been absent from school for weeks to months felt isolated and depressed. Focusing on positive thoughts and activities was reported to improve the pain. The abdominal pain could be considered a manifestation of mental problems.

Conclusions Thinking differently about the symptoms reduced the FGIDs for the children and adolescents. The treating physicians as well as parents and teachers need to help the child focus on changing the mindset of pain.

Strengths and limitations of this study

- The first author had interviewed the children's and adolescents' parents two times earlier and she, therefore, knew their pain histories.
- The first author carried out all the interviews.
- The use of semistructured interviews enabled detailed information about the children's and adolescents' functional gastrointestinal disorders.
- The sample size is small and only children from well-integrated families were interviewed.

INTRODUCTION

Functional gastrointestinal disorders (FGIDs) are characterised by pain and chronic or recurrent digestive symptoms without an underlying somatic disease or biochemical abnormality. The Rome criteria have become the standard for defining FGIDs.[1] FGID diagnosis in childhood has no biological markers and is based exclusively on symptoms reported by the child and their parents.[1] The pioneering paediatrician John Apley wrote in 1958: 'It is a fallacy that a physical symptom always has a physical cause and needs a physical treatment.[2] A study from 2020 of Egyptian children aged 4–18 years reported a prevalence of 30.4% of FGIDs, with irritable bowel syndrome the most common type of FGIDS.[3] In 2016, the prevalence of FGIDs among children and adolescents aged 4–18 years in the UK was 23%.[4]

For a study published in 2018, we interviewed parents of 14 children aged 6–13.5 years with FGIDs.[5] These children had been examined in a local hospital and were discharged without a somatic diagnosis. From that study, we concluded that FGIDs in children and adolescents are challenging for both the patient and their family, and that they often need long-term medical support.[5] In 2019, we interviewed the same parents again.[6] At that time, they continued to express needing a diagnosis and more information from physicians. All parents thought that the abdominal pain had a physiological cause, some parents thought, however, that problems at school or with friends could influence on the abdominal symptoms.[5 6] Some confirmed that they had left the conversation with the child about FGIDs to the physician, the psychologist and the teacher, often because they thought it was too difficult for them as parents. The parents also stated that they did not know the reason to the child's symptoms, but they suspected that it could be allergy or intolerance. The idea that mental problems could influence on the symptoms was seldom discussed with the child.[5 6]

In clinical work, however, questions about somatic and psychiatric symptoms should also be addressed to the children, as parents and teachers do not always recognise children's symptoms.[7] Thus, the aim of the present study was to learn more about the child's and adolescent's own experiences with FGIDs, not only how the pain affected their lives but also how the children and adolescents in retrospect reflected on the power that the pain had over them. To our knowledge, no previous in-person interview study has been conducted with children and adolescents with FGIDs whose parents have been previously interviewed two times about the same subject.

METHOD

The qualitative study was based on interviews conducted in Norway.

Patient and public involvement

Patients and the public were not involved in any ways.

Participants

In 2016, the first author interviewed 15 parents of 14 children with FGIDs, aged 6–13.5 years.[5] The children and adolescents had been referred by their general practitioner (GP) to a city hospital that serves around 500 000 inhabitants. Neither their GPs nor the hospital had found an explanation for these children's pain. The only exclusion criterion for the study was an inability to communicate in Norwegian. Data saturation was discussed in the article from 2016.[5] In 2019, all parents were interviewed again about the current situation for the children and their families.[6] Even though 4 years had passed since the children and adolescents were examined in hospital for the first time, the parents' described that some of the children still suffered from FGIDs.

In spring 2020, the families were contacted by phone, this time, for the purpose of interviewing the children. Among the 14 children whose parents had been interviewed, 12 agreed to participate (6 boys, 6 girls). At that time, the children were 10–18 years old. The two non-responders were a child with other physical challenges and a child who did not want to participate. Further recruitment details have been published previously.[5]

Interviews

The interviews were carried out by the first author, a female GP and child and adolescent psychiatrist. She presented herself as a researcher with no therapeutic involvement or treatment responsibilities. All interviews were conducted during May and June 2020 as video conferences due to the COVID-19 pandemic. Three children brought their mother to the interview. An interview guide was used and tested in one pilot interview but was not provided to the participants (figure 1). Field noted were made during the interviews. Repeat interviews were not carried out.

Interview guide (children and adolescents).

1. Do you have abdominal pain these days?
2. Can you tell me about the last time you had abdominal pain? Can you describe the pain? Has there been any change in the pain?
3. What do you do when you have abdominal pain? At school? During the weekends? During your spare time? During your holidays?
4. Is there anything you can do to improve the abdominal pain? Have you taken 'painkillers'?
5. How do your father, mother and siblings react when you have abdominal pain?
6. How do you experience the situation at home when you have abdominal pain?
7. What do you think causes your abdominal pain?
8. Have your parents explained the abdominal pain to you?
9. What was it like to be in the hospital for examination? Have you been to the GP?
10. Have you seen therapists other than the medical doctor? Alternative therapists?
11. What might make you feel secure about the abdominal pain?
12. Is there anything else I should have asked you about the abdominal pain?
13. How was it to be interviewed?

Figure 1 Interview guide (children and adolescents). GP, general practitioner.

Both the child/adolescent and their parents received written information about the study. The parents signed and returned the consent form. Participants over age 16 years signed on their own behalves. The audiotaped video conference interviews lasted 25–60 min. The transcripts were not returned to the participants for comments.

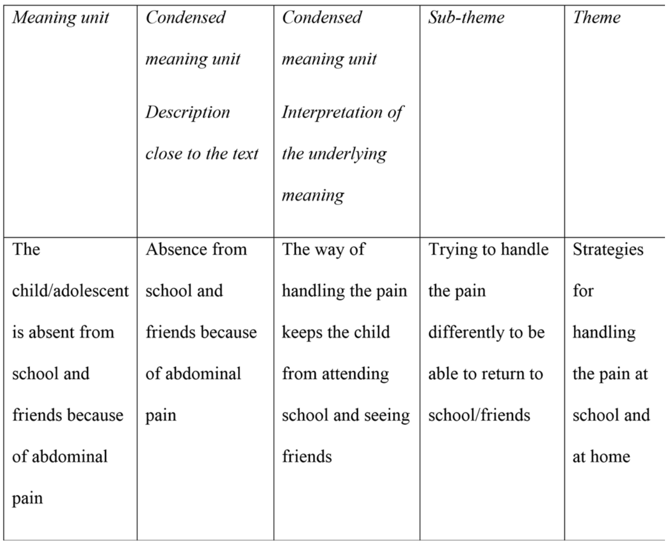
Data analysis

The first author recorded and transcribed the interviews. Both authors read the transcripts individually and collaborated on the analysis. Qualitative content analysis was applied, as described by Graneheim and Lundman.[8] Meaning units were found, shortened and coded. The codes were grouped into categories and subcategories to identify three main themes as shown in figure 2. No software tools were used for analyses. The themes were derived from the data, not identified in advance.

Reporting of the study follows the Standards for Reporting Qualitative Research[9] and includes the Consolidated Criteria for Reporting Qualitative Research checklist (online supplemental appendix 1).

RESULTS

Twelve children and adolescents aged 10–18 years were interviewed. Nine of the children had Norwegian parents and three had parents of foreign origin who had lived in Norway for several years. Two of the children lived with a stepparent. Eleven children had siblings; eight had



Meaning unit	*Condensed meaning unit* *Description close to the text*	*Condensed meaning unit* *Interpretation of the underlying meaning*	*Sub-theme*	*Theme*
The child/adolescent is absent from school and friends because of abdominal pain	Absence from school and friends because of abdominal pain	The way of handling the pain keeps the child from attending school and seeing friends	Trying to handle the pain differently to be able to return to school/friends	Strategies for handling the pain at school and at home

Figure 2 Examples of codes, condensed meaning units, subthemes and themes.

one sibling, two had two siblings and one had three half siblings.

At the time of the interviews, eight children (four boys and four girls) had recovered from their abdominal pain; four (two boys and two girls) had improved symptoms. We also know—from our interviews with their parents—that the two non-participating children had recovered from their FGIDs.

We identified three main themes in the current interviews with the children and adolescents:

1. Feeling isolated and depressed.
2. Strategies for handling the abdominal pain at school and at home.
3. The need for a diagnosis and information.

Theme 1: feeling isolated and depressed

The pain prevented most of the children and adolescents from being social and participating in leisure activities. They reported that the pain controlled their lives in many ways. Some had told their friends about the FGIDs and that it could be difficult for them to go to school or participate in other activities. However, others did not want to inform their school or friends about the FGIDs because it made them different from other children. Consequently, they tried to hide their symptoms: *I want to be like everyone else and not pay attention to the stomach pain* (interview number 8).

Being dependent on having a toilet nearby could also be embarrassing for the children and restricted them from school or other activities, which in turn aggravated the situation. They felt isolated and the situation affected their mental state. These children and adolescents reported mental symptoms ranging from feeling sad to being deeply depressed and needing psychological treatment. The fact that the FGIDs hindered them from doing positive activities worsened their mental state: *I love playing basketball, the fact that the stomach pain has stopped me from playing during long periods made me deeply depressed* (interview number 6).

The FGIDs could cause major consequences for the whole family, such as work absence, economic impacts and worried siblings. The children reported having a bad conscience, feeling guilty and ashamed of their family's difficult situation. This became another burden, in addition to the FGIDs and absence from school and social life, which further reduced their mental state.

Some of the adolescents reported seeing the abdominal pain as a manifestation of mental problems. Reaching this insight had been time-consuming and required professional assistance but was described as a sort of revelation leading to a new understanding of a complicated problem.

Some reported escaping from their mental problems by using somatic symptoms. The youngest children in the study also seemed to be aware of this phenomenon: *The stomach pain came in the evening or in the morning on days when I should do something difficult at school* (interview number 7).

Theme 2: strategies for handling abdominal pain at school and at home

Nearly all the interviewed children had experienced FGIDs both at home and at school. The frequency and intensity of their pain differed markedly, independent of where they were. School absence affected both their academic situation and daily contact with friends. The FGIDs made it difficult to concentrate on schoolwork. Three of them (two boys and a girl) missed several weeks of school, while four always remained at school despite their stomach pain. Two adolescents reported that their teachers were unaware of their FGIDs and how it affected them: *I had a lot of absence from school. I do not think the teachers knew much about the pain. I had to explain to the teacher myself each time* (interview number 9).

In some cases, the parents had informed their child's school about the FGIDs and had made arrangements, so that it was easier for the child to stay at school during pain episodes: *We had arranged with school that I could sit in another room and read when I had stomach pain. Therefore, I never left school because of stomach pain* (interview number 1).

The children reported both that they thought they experienced FGIDs because they did not like school, and, the opposite, that they missed going to school when they stayed home because of pain. Some reported having used the FGIDs to convince their parents that they needed to stay home from school: *If I wanted to stay home from school the next day, I asked for some food that gave me stomach pain* (interview number 3).

The children had different ways of handling their pain at home. It could be reduced or worsened by food or drinks like milk, wheat products and vegetables. Others reported positive effects of a warm bath, lying down on the floor to relax or going to the toilet. Eight children had taken analgesics, with varying effects. Two reported that medicine reduced their FGIDs, while six were unsure. Some of the children reported handling their FGIDs by shifting their focus from the pain to a positive activity, such as football, gaming, etc. Some children had discussed these methods with their parents or a psychologist, while others experimented on their own: *The pain was reduced when I distracted myself. When I played football, I never noticed the pain. I was so set on playing* (interview number 1)*; When I was gaming with my friends, I stopped thinking about the stomach pain* (interview number 6).

Even the younger children reported that thinking about their pain made it worse: *I thought hurts, hurts, hurts and then the pain became worse. Then I did something I liked to do, and the pain disappeared* (interview number 9).

However, they also reported that there often was nothing to do but wait until the pain disappeared. No medicine or other treatments were available at school; therefore, it was better to go home: *I usually call my mother, who picks me up and we go home* (interview number 7).

Based on the information provided by the children, parental involvement and interventions varied. Few had the impression that they had discussed the pain with their parents. However, many said there was not much the parents could do because nothing helped their FGIDs.

None of the children in our study had involved their siblings in their FGIDs. Nor had they thought much about the fact that their symptoms could have a marked effect on their siblings.

Theme 3: the need for a diagnosis and information

These children and adolescents were clear in their expressions that they needed to know what was wrong with their stomach. They reported that uncertainty about their diagnosis made the situation worse. It was difficult for them to understand that there was no medicine or treatment to reduce or remove the pain and provide a more predictable daily life. During pain periods, they never knew how the day would go or whether they would be able to participate in various activities. Some were afraid of having a serious disease, which they feared further examinations would reveal. Some shared these thoughts with their parents, while others kept them to themselves.

Some children even asked questions of the interviewer because they did not know who else they could talk to, except for their parents: *There was a girl at school who had cancer. I thought that I also could have something similar. I did not know who I could ask about this* (interview number 6).

These children and adolescents emphasised that information concerning their symptoms and diagnosis from physicians was important. They felt they had been well cared for in the hospital, even if some missed out on receiving information because it was not communicated on their level. When the FGID diagnosis and other information were conveyed to the child in a way they understood, this positively affected their abdominal pain: *When they found out what this pain was, I started to feel better at once and the pain disappeared gradually* (interview number 12).

Some parents tried to explain and discuss the FGIDs with the children. However, direct psychoeducation from the doctor was important to the children and could change their situation. Explanations that these symptoms were not dangerous, that the pain would be reduced over time and that it was important to go to school improved their situation. Drawings of the intestinal tract, stool quality, etc were remembered by the youngest children and helped them understand more of their symptoms: *I asked the doctor. She said she thought the pain would gradually be reduced and disappear. That helped me a lot. Until then, I had thought the pain always would be there* (interview number 1).

Three of the children had talked to a child and adolescent psychologist, another had requested an appointment, but this request was not fulfilled. Two children sought guidance from a family member with psychological expertise.

DISCUSSION

Twelve children and adolescents with FGIDs were interviewed, after their parents had been interviewed in 2016 and again in 2019. Eight of the children had recovered from the FGIDs and four had reduced symptoms. Three of the adolescents had weeks or months of school absence. We noted that all children were concerned about keeping in contact with friends and being able to continue sport activities and hobbies. They underlined that focusing on something positive could reduce the pain. Their FGIDs could also hide other difficulties, such as psychological problems, which manifested as pain. Information and psychoeducation from their physicians were important to these study participants.

Theme 1: feeling isolated and depressed

Many of these participants reported feeling lonely, socially isolated and sad; some even reported deep depression. Research supports the concept that recurrent and persistent abdominal pain can be a prodrome of depression and anxiety, or vice versa, in young people.[2 7 10] It is also well known that loss of pleasure, changes in life and stressful life events are factors that may lead to depression or other psychiatric symptoms. We could not determine whether our participants' psychosocial issues preceded their somatic complaints or resulted from them. The biopsychosocial model of illness is based on this complex interplay of genetic, environmental, physiological and psychological factors and their influence on symptoms.[1 11]

Consistent with other studies, it is safe to assert that adolescent patients with chronic somatic reports are more likely to experience significant anxiety, depression and psychosocial or environmental stressors.[12] Some of the children and adolescents in our study expressed a deep sense of despair and hopelessness, which may lead to serious and long-lasting problems. Physicians should, therefore, be careful to investigate these symptoms.[12]

Besides having FGIDs, we found that these children felt ashamed of not being in school and guilty about their parents' missing work. Some of these children kept such feelings to themselves because they thought they were too embarrassing to talk about. According to studies by Khan, it is important to identify emotional or psychological stressors to help both the child and their parents understand the child's reactions and feelings and to support the child in this process.[13] In our experience, openness about such issues with school, friends, etc often improves the child's situation.

It has been emphasised that the goal of managing FGIDs is to provide a satisfactory quality of life through support, education, medications, and better coping skills. Reassurance about the positive outcomes of FGIDs and positive aspects of the child's health are crucial.[13]

Theme 2: strategies for handling the abdominal pain at school and at home

Providing the child and their parents with information about the importance of trying to attend school, even on days when the child has abdominal pain, is a prominent part of treatment for FGIDs.[14 15] Being at home instead of at school or work may seem like the easiest solution; three of the adolescents in our study had months of school absence. Some of the youngest children in our study reported calling their parents and being brought home when their FGIDs increased at school. Our study illustrates that it is difficult for parents to refuse to pick their child up from school during pain periods. As stated by Lowth, the child should not associate pain with removal from normal activities but should understand the importance of maintaining routines and staying at school during pain periods.[14] Others have emphasised that teachers need reassurance and information that the abdominal pain is functional, while acknowledging that it is genuine. The advice is clear: pain during class should be managed through continuation of the usual routine.[16]

Parents' reaction to their child's pain is increasingly recognised as an important moderator of the child's outcomes and has become an area for clinical intervention.[17] According to van Tilburgh, a supportive and understanding home environment is important for helping the child recover from pain. Parents look to clinicians for help and are open to discussing both medical and behavioural approaches to their child's pain. Their role may be difficult, and they also need physician support.[18] Some children and adolescents in our study had talked to their parents about their FGIDs, but most reported not having helpful conversations about hope for recovery. The fact that all parents stated that the pain mainly had physiological causes gave the children little support in the belief that it also could have mental causes.[5 6] Parents should be advised to reduce concerned responses to their child's pain and to focus on distraction instead.[19] Lowth stated that the most important therapeutic steps are to explain the diagnosis, develop strategies to cope with stress and provide reassurance that there is no serious underlying disease.[14] Others have described that the parents' acceptance of a biopsychosocial model of illness is important to the resolution of FGIDs in children.[16 20]

The children in our study had not involved their siblings in their FGIDs and did not think it was important to do so. Similarly, Gan found that many siblings were overlooked, and that they experienced difficulties with schoolwork, decreased school attendance, academic dysfunction and perceived differences in peer and teacher interactions. A school-based sibling support model combining sibling and teacher, psychoeducation and individualised psychological support has been suggested, in which parents and schools are advised to normalise the siblings' experience and reaction, with consistent support.[21]

The children and adolescents in our study who had been referred to a child and adolescent psychologist or psychiatrist reported positive experiences. Other studies have found that various psychological therapies reduce pain. Cognitive behavioural therapy has effectively reduced the recurrent abdominal and other types of pain.[19 22] Other methods like relaxation exercises and hypnosis have also been tried.[13] The current focus is increasingly on pain-specific cognitions and coping strategies, including disease threat and catastrophising.[23]

Theme 3: the need for a diagnosis and information

A study from 2018 stated that the most important step in treating FGIDs is a correct diagnosis.[24] The participants in our study also emphasised that diagnosis and information about the disease are crucial to improving their situation. One challenge with this diagnosis is helping patients understand that even if there is no underlying organic disease, FGIDs cause symptoms such as abdominal pain. One study noted that children need medical treatment to relieve their symptoms, even if there is no organic cause for them.[24] In a study among children with functional nausea and their mothers, they also expressed the desire for a clear medical diagnosis and treatment and recognised the significant impact of the symptoms on the adolescents' mental health and social functioning.[25] A Canadian study from 2013 also emphasised that uncertainty about the diagnosis was difficult for families where a child suffered from FGIDs.[26]

The importance of children's needs and rights to information about their diseases and symptoms are manifested in the United Nations Convention on the Rights of the Child from 1989, in which article 24 'Health and Health Services' describes children's and adolescents' right to.[27]

Information dissemination has been discussed elsewhere. Damm stated that effective communication skills are important when assessing and treating a child's subjective pain symptoms. Without the child's contributions to the conversation, understanding the nature and severity of their pain is difficult.[28] We found that the patients' understanding and acceptance of information about their symptoms is crucial to their treatment course. Physicians' reassurance that their young patients have understood the information they provided is also important. Street stated the importance of physicians providing both qualitative and quantitative information.[29] This was underlined by an adolescent in our study who reported that from nearly the first moment when his physician explained that his pain was not serious, it decreased and gradually disappeared. This also coincides with other researchers' report that communication is the most common and essential medical 'procedure'[30] and that, furthermore, effective and adapted communication is essential for accurate diagnosis, successful treatment and enhanced patient satisfaction.[31]

Strengths and limitations

The interviewer is herself a GP and child and adolescent psychiatrist and has long experience conversing with children and adolescents. She introduced herself as a researcher without clinical responsibility for the interview subjects' symptoms. Due to the COVID-19 pandemic, the interviews were conducted as video conferences. This could reduce spontaneous statements and non-verbal communication, however, is could make it easier for the children and adolescents to provide sensible information. The children and adolescents had been examined in hospital 4 years before the interviews. We think that they could have forgotten some details about their FGIDs, but the retrospective view of the situation gave valuable considerations and reflexions about their FGIDs and what had reduced the symptoms. Three of the youngest children sat together with their mothers during the interview, which could influence some of the answers, especially the questions about the parents' involvement in the pain situation. However, the presence of the mothers seemed to make these children less nervous and more relaxed in the interview. The analysis could have been affected by the fact that we knew from our two earlier studies that the parents thought the symptoms were mainly a physical condition.

CONCLUSION

FGID in children and adolescents is a complex disorder that affects their home, school and friend situations. These children often feel isolated, sad and depressed, and they need more information and better explanations about their symptoms. Treating physicians, schools and parents must all be familiar with the child's situation. Treatment should include adapted psychoeducation, referral to a child and adolescent psychologist may also be necessary.

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Contributors Both authors meet the ICMJE criteria for authorship. The paper was conceived by AB and MB. MB applied for ethics approval. AB carried out the interviews and transcribed the text, and both authors participated in the analysis. AB drafted the article, and MB revised it critically.

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Competing interests None declared.

Patient consent for publication Not required.

Ethical approval The Norwegian Regional Committee for Medical and Health Research Ethics—REC South-East C—approved the study (reference number 2020/93964). The study followed the operational principles of the Declaration of Helsinki and adhered to the Belmont Report principles (ie, respect for persons, beneficence, justice) in obtaining valid informed consent from parents. Parents gave written consent to participate. Children and adolescents were informed about the study through an information letter. Children 16 years and older signed their own consent.

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PAPER IV

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General practitioners’ experiences with children and adolescents with functional gastro-intestinal disorders: a qualitative study in Norway

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ORIGINAL ARTICLE

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General practitioners' experiences with children and adolescents with functional gastro-intestinal disorders: a qualitative study in Norway

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ABSTRACT

Objective: Functional gastrointestinal disorders (FGIDs) are common in children and adolescents. During 2016 and 2019, we investigated the experiences among parents of children with FGIDs and interviewed their children and adolescents during 2020. The aim of the present study was to explore the experiences among general practitioners (GPs) who treat this patient group.
Design: Individual interviews with open-ended questions were audio recorded and transcribed, and subsequently analysed using descriptive content analysis.
Setting: Urban and rural areas in two municipalities in Southern Norway. Participants: Twelve GPs practicing in the region were interviewed.
Results: GPs generally feel competent treating these patients without referring them to hospital or specialists. Having known the patients and their families over time is important. Providing psycho-educational resources to the patients and parents is essential for their understanding that the pain is not dangerous. The importance of attending school was emphasised.
Conclusions: The GPs' biopsychosocial focus and long-term follow-up care are essential in treating children and adolescents with FGIDs and their parents.

KEY POINTS

Current awareness

- Abdominal pain is a common symptom in children and adolescents, for which an organic cause is seldom found.

Main statements

- GPs feel competent to treat children and adolescents who have functional gastro-intestinal disorders (FGIDs) without referring them to hospital or specialists.
- A main task for GPs is to inform children, adolescents, and their parents that FGIDs are not a serious organic disease and that everyday life should continue.

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KEYWORDS
Children's health; functional gastrointestinal disorders; qualitative research; general practice; family medicine

Introduction

Children and adolescents with functional gastro-intestinal disorders (FGIDs) are frequently seen by general practitioners (GPs [1–3]). In Norway, 8.4% of children between 6 and 15 years visited their GP for gastro-intestinal symptoms in 2019 (Statistics Norway). A study from the Netherlands found that for around 80% of children who consulted their GP for abdominal pain, the final diagnosis was 'functional abdominal pain' [1]. In 1958, John Apley, a British paediatrician, published his pioneering research in children with functional abdominal pain, which he labelled recurrent abdominal pain (RAP) syndrome [4]. He found that 11% 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' [4]. Since then, the term RAP has been replaced by FGIDs, as defined by the Rome criteria [5]. The prevalence of FGIDs using the Rome IV criteria in children ranges from 21 to 25% [6]. The worldwide pooled prevalence of FGIDs in children 4–18 years old is 13.5%. However, the prevalence across studies varies widely from 1.6 to 41.2% [7]. FGIDs are characterised by chronic or recurrent digestive symptoms without an underlying

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somatic disease or biochemical abnormality [5]. In the ICPC system, we would code it D87 Stomach functional disorders or D93 Irritable bowel syndrome [8]. The abdominal pain may also be a somatic feature of underlying emotional stress including anxiety and depression [9]. The diagnosis is exclusively based on symptoms reported by the children and their parents. The condition has no biological markers.

GPs often follow these patients the entire course of the disease. Either they remain in primary health care or they are referred to a specialist and return with no somatic diagnosis. The patients' family histories are often well-known to the GPs, who can be important informants about this patient group over time. It may be demanding for GPs to provide meaningful help to their young patients with FGIDs, as long as there is no physical explanation for their pain [10]. They struggle with the incongruence between patients' symptom presentations and the explanatory models for biomedical disease [10]. Building a good doctor-patient relationship may be challenging. It is therefore important to explore the GPs' experiences, how they manage to relate to these families and what they have found out can be a useful help for the children and adolescents with FGIDs and their families.

In 2016, the first author interviewed the parents of children and adolescents aged 5–15 years with FGIDs who had been referred to a local hospital by their GPs, and who was later discharged without a somatic diagnosis [11]. In 2019, the parents have interviewed again [12]. The parents reported in both studies that in their opinion the symptoms had a physical cause, though some thought that problems in school and with friends could aggravate the symptoms. The parents wanted a diagnosis for their child and follow-up by a physician. In 2020, the children and adolescents were interviewed [13]. Some of them were afraid the gastrointestinal orders were caused by a serious disease, and they also wanted a diagnosis and follow-up by a doctor.

The aim of the present study was to investigate GPs' experiences with treating children and adolescents with FGIDs. How did the GPs succeed to balance the biopsychosocial aspects, the somatic examinations, and the maintenance of trust in the doctor-patient relationship? We also addressed the GPs' views on the types of approach and treatment these patients and their families may need.

Material and methods

Ethical approval and consent to participate

The Regional Committee for Medical and Health Research Ethics determined that the study did not need their approval (reference no. 2020/184272). The Norwegian Centre for Research Data approved the study (reference no. 2020/349340). The GPs gave written consent to participate.

Study design

We chose a qualitative study design based on individual interviews with Norwegian GPs. The qualitative research interview tries to understand the world from the interviewee's side and to bring out the meaning of their experiences [14]. Because of the Covid-19 pandemic, we choose telephone interviews [15]. The study was based on the biopsychosocial model, which emphasises an intricate blend of biological and psychosocial dimensions of medicine [16]. In the interviews as well as the analysis and discussion of the study, this complex interaction in understanding health, illness, and care was central.

The study was designed according to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) criteria [17].

Table 1. Interview guide used with the GPs.

1. How often do you see children or adolescents with long-term or chronic abdominal pain?
2. What do you do when a child or adolescent presents with chronic abdominal pain?
3. Do you have any thoughts about contributing factors or conditions that may provoke or increase abdominal pain?
4. Do you have any impressions about how the pain affects the child's family?
5. Do you refer any of these patients to a hospital or a specialist? If yes, whom?
6. If a child or adolescent has been seen by a specialist and returns to you without a physical diagnosis, what do you do?
7. As a GP you have a busy day with 15–20-min consultations; how is it possible to follow up with these patients?
8. What is your impression about what these patients and their families need?
9. Do you usually contact the patient's school about measures that could make the school day easier for the patient?
10. Do you know how these patients are doing over time?
11. Do you (as a GP) have any advice about following up with children and adolescents who have functional abdominal pain? What do you think may help them?
12. How do you experience the consultations with these patients and their parents?
13. Is there anything I should have asked you that has not been asked in the interview?
14. How was it being interviewed about these patients?

Interview guide

A semi-structured interview guide with 14 open-ended questions and additional follow-up questions was developed (Table 1). The questions were developed to discuss the issues that had been presented by the parents, children, and adolescents in our former studies [11–13]. We formulated the questions based upon the biopsychosocial view on health and illness. After two interviews, the researchers evaluated the guide and made small modifications.

Participants

During autumn 2020, GPs working in the same region as the children and parents whom we previously interviewed were selected from a regional list and contacted by telephone by the first author for an interview. Fourteen GPs were contacted and asked to participate. Eight female and four male GPs aged 36–67 years accepted the invitation and were interviewed. These were not the GPs of the specific patients whom we had interviewed previously. Two GPs who had accepted the invitation withdraw without giving any reason. This was a strategic sample based on age, gender, urban or rural practice, and predominance of immigrants or Norwegian inhabitants (see Table 2).

The Norwegian GP system

In the Norwegian list system, the patient chooses a GP and then ‘belongs’ to this physician. The relationship usually lasts several years and, consequently, the GP generally knows the family’s histories well and can use these experiences as valuable information in the consultations. In Norway, GPs’ consultations usually last 15–20 min.

Table 2. Characteristics of the interviewed GPs (*n*).

Age	Male	Female	Specialist	Urban practice	Rural practice
30–40	1	1	0	0	2
40–50	0	2	2	1	1
50–60	1	4	5	2	3
60–70	2	1	3	2	1

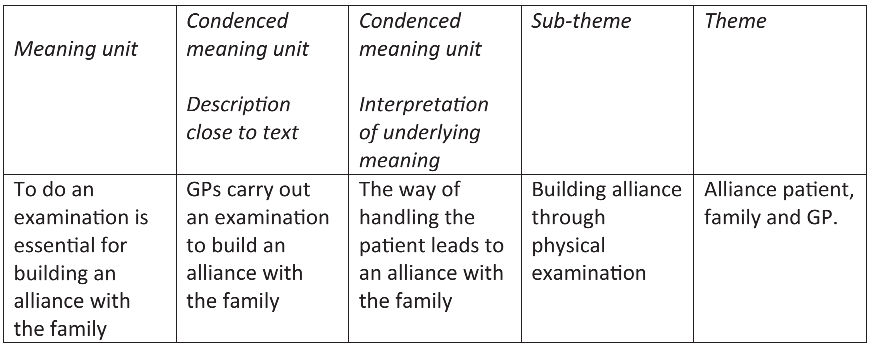
Data collection

The first author, a female former GP, and child and adolescent psychiatrist, interviewed the GPs. They were informed that she was interviewing them in her role as a researcher. The GPs determined an appropriate time for the telephone interview. Written information about the study was sent to the GPs before the interview. The interviews were conducted during October and November 2020 and lasted 16–40 min. During the last 2–3 interviews, we got no more information or details. Data saturation was thus achieved, and recruitment was concluded [18].

Data analysis

The interviews were audiotaped and transcribed by the first author. Qualitative content analysis was conducted based on the work by Graneheim and Lundman [19]. No software tool was used for analyses. Both authors, the other also a female GP and an experienced academic, read the transcripts individually and discussed their interpretations to achieve a common understanding and reinforce the level of trust and credibility [19]. Any disagreement was discussed until a solution was reached that both could agree with. The interview texts were sorted and coded into meaning units, abstracted into sub-themes, which through reflections were unified into themes, as shown in Figure 1. The biopsychosocial model also provided a basis for the final themes.

The idea for the study was conceived by AB and MB. MB applied for the approvals. AB carried out the interviews and transcribed the text, and both authors



Meaning unit	*Condensed meaning unit* *Description close to text*	*Condensed meaning unit* *Interpretation of underlying meaning*	*Sub-theme*	*Theme*
To do an examination is essential for building an alliance with the family	GPs carry out an examination to build an alliance with the family	The way of handling the patient leads to an alliance with the family	Building alliance through physical examination	Alliance patient, family and GP.

Figure 1. Examples of codes, condensed meaning units, sub-themes, and themes.

participated in the analysis. AB drafted the article, and MB revised it critically.

Results

The GPs' practices were in both rural and urban regions, and one included a predominantly immigrant population (Table 2). The GPs reported—some after looking in their files—to have appointments with 1–10 children and adolescents (aged 5–18 years) with FGIDs each month.

We identified three main themes:

> Building an alliance with the patient and the parents in a complex situation.
>
> Healthy children with abdominal pain- expanding the patients' and parent's understanding of FGIDs.
>
> The pain should not control their life-changing the patients' and parent's reaction to FGIDs.

Building an alliance with the patient and parents in a complex situation

The participating GPs highlighted the importance of trust and alliance between them, the patients, and their parents as being a prerequisite for making any progress in handling abdominal pain. Their approaches to these patients had the underlying aim of building and enforcing such an alliance. Even if dealing with the families' complex problems could be challenging, the GPs were clear that children with FGIDs should be followed up in primary care.

All GPs emphasised that a physical examination, including blood tests, urine, and stool samples, was absolutely necessary to exclude organic disease when a child presented with abdominal pain. If the examination showed organic disease, the patient was referred for further evaluation. All GPs claimed that the medical examination seldom showed organic abnormalities that could explain the abdominal pain. Anyhow, it was important to be able to inform the patients that the pain was not dangerous. To do an examination was also essential for building an alliance with the family.

A conversation with the child or adolescent and parents about the symptoms was highlighted as important toward deciding how to proceed. Questions about family conditions, siblings, school, friends, and other possible stressors were asked. The GPs tried to have a brief, private conversation with adolescents and children from 5–10 years, when possible. A trustful relationship between the doctor and the family was highlighted by the GPs as essential for the patients and parents to follow their advice. The GPs stated that although abdominal pain in children generally has no organic cause, it affects the lives of the child and family, and they emphasised showing empathy and support during difficult times, thus showing that they took the pain seriously. Children and adolescents with FGIDs often presented complex problems. Some GPs stated that these consultations could be challenging, especially when the patient returned from the hospital without findings of any somatic diagnosis:

> We do not struggle with the patients who have a disease, it is the patients without a diagnosis who can be challenging (Interview 10).

Yet, the GPs referred few patients with FGIDs to the hospital. They argued that these patients belong in general practice:

> These patients belong here with me, but if the dialogue is complicated, I refer them to hospital for a second opinion (Interview 1).

Other reasons for referrals were alarm or 'red flag' symptoms, a diffuse or long-term pain situation, the parents demanding to see a specialist, often a paediatrician, or the GP needing support from a colleague:

> Intensity and chronicity determine whether they are referred. As a doctor, I may need colleague support, because the patient and families become so dissatisfied if they don't get well (Interview 10).

Toilet habits and constipation were factors that the GPs saw as problematic for many of these patients. Teaching them about how the body functions, which is really a parenting task, often helped the children. Concrete advice about daily toilet routines, as well as about food and exercise, was also needed:

> A gut reaction to strawberries does not mean intolerance and does not mean that it is impossible for the child to eat this food (Interview 4).

The GPs received requests for diet advice and 'quick fix' treatments from patients and parents, who wanted medicine that would eliminate the pain once and for all. The GPs spent a great deal of time explaining to the patients and the parents that their advice must be followed for a long time to be effective, as there is no quick and easy way out of FGIDs.

> They returned for a new consultation after some month. The advices I had given them earlier had not been followed. They asked for a referral to hospital for a quick treatment (Interview 9).

Some of the GPs wanted better access to child and adolescent psychiatrists as well as nutritionists outside the hospital. They expressed that a few hours of guidance from a specialist could probably help keep the patient out of the hospital and accelerate improvements. All GPs in our study mentioned that most of these child and adolescent patients with FGIDs disappeared from their practice after some time. When this occurred, the GP concluded that the patient had recovered. However, some returned, even years later, with the same symptoms. Others returned with mental health problems, such as anxiety or depression. The GPs emphasized that trust and alliance were necessary for these patients to consult them with mental symptoms.

Healthy children with abdominal pain—expanding the patients' and parents' understanding of FGIDs

By using the biopsychosocial model, the GPs could bring in other dimensions than the physical disease when it came to understanding and treating the FGIDs.

> Their stomach controls their life. They are quite healthy children, except from having abdominal pain (Interview 9).

Some patients and their families consulted the GP often and as soon as the child felt pain or had any digestive symptoms. They were afraid of serious diseases and needed their GPs' reassurance. Some of the GPs in our study had been their family doctor for many years and recognised the parents' approach to pain symptoms. When the clinical examination was normal, the GPs emphasized other causes than the organic disease. They highlighted that the patients', parents', and teachers' understanding of the pain in a biopsychosocial context is crucial. This would move the families' away from the fear of serious somatic illness and allow them to explore the context in which the pain occurs. One GP in our study claimed that saying the words 'this is not cancer' (Interview 9) was important. Hearing this was sometimes sufficient, after which both the patient and parents stopped worrying about the symptoms and the pain improved:

> Not everything that hurts is dangerous. However, children are honest, and we need to take them seriously. (Interview 4).

The GPs were also concerned with somatization in both parents and patients because pain can be an expression of mental or social difficulties:

> Children feel through the stomach. The cause of the pain often is multifactorial, the child's way of signalising problems is through pain. (Interview 8).

Being able to understand the child's life situation through the biopsychosocial model, gave the GPs in our study tools to help the children and their families. Receiving an explanation for FGIDs and a diagnosis was described by the GPs as being among the most important factors for recovery or living a high-quality life with the symptoms:

> In the second consultation, I always ask about school/work, friends, family and mental symptoms and at last I ask what they believe is the cause of the pain (Interview 2).

The GPs seemed to see the pain in a holistic view. Their tasks would be to get the parents as well as the patients to see its connection with psychosocial factors. The GPs took on the task to expand the families' views and understanding, which could be challenging.

The pain should not control their life—changing the patients' and parent's reactions to FGIDs

Challenges at school often reinforced FGIDs, however, having morning abdominal pain should not mean staying home from school for the rest of the day. The parents needed the courage to send the child with abdominal pain to school. Providing teachers with an explanation about FGIDs and information about the child's situation, was also important. An essential message was that the prognosis for FGIDs does not improve if the child stayed home from school. Narrowing the patient's life based on their symptoms could negatively affect their daily experiences. The GP's task was to guide the patients and parents to this understanding:

> We need to get the parents and the teachers on the team. They all need more health competence. The next task will then be how to deal with the pain (Interview 4).

Parents are their children's and adolescents' teachers, so it is important to learn them to interpret bodily signs and how to respond to them. The GPs in our study, therefore, claimed that one of their important tasks was educating children and adolescents, as well as parents, in interpreting and handling abdominal pain:

> The parents need knowledge about the symptoms. They contribute to the child's fear by becoming anxious themselves (Interview 10).

The children 'inherit' their parents' bodily reaction to stress and their anxiety for serious disease. Knowing the families made it easier for the GPs to explore the situation through the biopsychosocial model:

> The children adopt their parents' ways of handling the pain (Interview 4).

The GPs in our study thought that children and adolescents could be symptom carriers for the families' problems. This was perceived as a complex situation that only emerged after exploring these problems for some time. The GPs emphasized that it was important for them to capture possible mental problems in these children and adolescents.

> Making the parents understand that this is a mental reaction and not a physical illness, is important (Interview 1).

> The children and adolescents need to have fun and experience a good life. That is maybe the most important treatment for these children with abdominal pain (Interview 10).

Discussion

Twelve GPs were interviewed about their experiences with treating children and adolescents with FGIDs. Our findings stated that it is their responsibility to follow up with these patients and that they feel competent handling the symptoms and seldom refer these patients to the hospital. The patients and parents need reassurance that the pain is not caused by a dangerous illness. They must also be taught the connections between FGIDs, emotions, and life situations.

Strengths and weaknesses of the study

The first author and interviewer is a child and adolescent psychiatrist who previously worked for many years as a GP. We considered this an advantage during the interviews, as the GPs felt at ease talking to a colleague. In-person interviews may have allowed more detailed information, than a telephone interview. The absence of visual cues *via* telephone is thought to result in loss of contextual and non-verbal data and to compromise report, probing, and interpretation of responses compared to face-to-face interviews. However, the telephone may allow respondents to feel more relaxed and able to disclose sensitive information [15]. A longer interview than 16–40 min could probably have given more and deeper information, but the GPs tight time table made this difficult. The GPs talked quite freely around the themes which gave us complex information. The follow-up questions in the interviews also gave knowledge unknown to the researchers. We continued interviewing until saturation was reached [18]. Despite this, we strove to include variability in interviewees' age, and practice location (Table 2). All GPs worked in the same region of Norway, and most of them were experienced physicians, which may be a limitation to the generalizability of the results. GPs in other parts of Norway might have had other experiences when it comes to referrals to hospital/specialists and how often the patient had the possibility to visit the GP [20]. There were just two authors in the research team. A larger research team could have expanded the discussion.

For qualitative research, theories are especially important as tools to understand, interpret, and elaborate on empirical observations beyond description [21]. The biopsychosocial model has been the basis for the present study.

Discussion of the results

Building an alliance with the patient and parents in a complex situation

Though organic pathology is seldom found, the GPs in our study saw physical investigations as important, in combination with conversation. Lowth concluded that an examination should be conducted to exclude organic disease [22]. This will also have implications for building the doctor-patient alliance. However, the potential for non-organic causes must also be raised early in the consultation, so that parents and patients are introduced to this way of interpreting the pain. Commencing the investigation before discussing this aspect, makes subsequent acceptance of a non-organic diagnosis more difficult [22]. In contrast, the early introduction of stress as a potential cause is likely to improve outcomes [23].

Whether further examinations should be conducted, the GPs in our study thought it depends on clinical findings, such as alarm or 'red flag' symptoms. Chiou and Nurko stated that in the absence of red flag symptoms, extensive investigations are usually unjustified [24]. This corresponds to our findings: Extensive investigations are clinically non-indicated, they are expensive, and tend to impair the physician–patient relationship and therapeutic alliance. They may send a message to the patient or parent that the physician is uncertain about the positive FGIDs diagnosis and reduce overall patient confidence in the care plan [24]. The GPs' in our study attitudes toward, and empathy for, their patients were emphasised, and it was stated that the physician–patient relationship is important for confidence in the treatment. Likewise, Levy and

Naliboff reported that even when a functional diagnosis is suspected, it is important for the GP to validate the patient's symptoms as real and to take their concerns and complaints seriously. The GP should adopt an active listening approach and an enthusiastic, positive, and encouraging attitude towards treatment [25]. Skirbekk emphasized the patients' trust in the physicians. The physicians were authorized by the patients to exercise their judgement as medical doctors to varying degrees [26]. The GPs in our study usually examined and treated children and adolescents with FGIDs themselves, seldom referring them to specialists or hospital. Other studies confirm this finding [27,28]. Patients with constipation who do not respond to primary care interventions, and those with more severe psychiatric symptoms or symptoms that affect family functioning, may benefit from referral to specialists [28].

Healthy children with abdominal pain—expanding the patients' and parents' understanding of FGIDs

In our study, the GPs observed a pattern in which some parents themselves had visited the GP with FGIDs or other pain symptoms for years. This pain approach seemed to have been inherited by their children or adolescents and could also be an expression of the parents' worries, anxiety, or bodily reaction to stress. This tendency has been noted previously. Shraim reported that consultations for non-specific physical symptoms (NSPS) in mothers were a risk factor for repeated consultations for NSPS in their children [29]. Overall, this was associated with maternal–child consultations for painful NSPS including gastro-intestinal, musculoskeletal and neurological symptoms [30]. There are several possible reasons for this behaviour; however, the GPs in our study were more concerned with the consequences. The biopsychosocial model of chronic pain helps to explain how physiologic and psychological factors and social context dynamically interact and contribute to the experience of pain [31,32]. A clear explanation of this model enables patients and families to better describe what they experience [33]. A study from 2018 stated that education in recognising emotions and an awareness of the relationship between emotions and bodily sensations in primary school-age children could help prevent somatization and pain in later life [34].

The pain should not control their pain-changing the parents' and patients' reaction to FGIDs

The GPs in our study stated that both parents and teachers need to change their reactions to the child's or adolescent's abdominal pain. A study from 2009 confirmed the view that the parent's job now is to be a 'coach', to encourage and support [35]. The child's return to normal activities was highlighted; children must learn to function with discomfort if they are to complete their education [35]. Newton underlined that parental reaction to a child's pain is increasingly recognised as an important moderator of outcomes and has become an area for clinical intervention [36]. The focus should be on a return to normal functioning rather than on the complete dissolution of pain [37]. The GPs in our study saw it as their job to educate the children about bodily signals and how to respond to them. They stated further that the body's language should be taught from the early years, with the parents as the primary teachers. The danger, however, could be that they inherited the parents' bodily reaction to stress. Consistent with other studies, the GPs on our study indicated that some of their young patients with FGIDs returned later with depression and anxiety symptoms. A study from 2020 stated that children and adolescents with FGIDs frequently have associated, adverse emotional well-being, including current or subsequent histories of depression, anxiety, unhappiness, and low self-perceived health status [9]. Although most children with FGIDs experience pain improvement over time, long-term follow-up studies have shown that a significant number continue to have symptoms after five years, or even into adulthood [38].

Conclusion

GPs in our study felt comfortable serving as the primary care provider for children and adolescents with FGIDs. Continuity, knowing the patients and their families over years, and having the opportunity to observe all their symptoms were considered important to GPs. Children can inherit their parents' bodily reactions to stress and carry the family's problems. Both the child and parents must learn that most pain is not dangerous. Instead, the focus should be on normality and mastering everyday life. The GPs in our study made it clear that investigation and treatment of children and adolescents with FGIDs does not have to be complicated, and that understanding the symptoms through the biopsychosocial model is essential.

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We are grateful to all the participating GPs for sharing their experiences.

Ethical approval

The Regional Committees for Medical and Health Research Ethics determined that the study did not need their approval (reference no. 2020/184272). The Norwegian Centre for Research Data approved the study (reference no. 2020/349340).

Disclosure statement

The authors report no conflicts of interest.

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