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Everyday life with childhood functional constipation: A qualitative phenomenological study of parents' experiences

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ABSTRACT

Childhood functional constipation (FC) is a worldwide problem with treatment regimens affecting everyday life.

Aim: To explore parents' experiences of living with a child with FC and its impact on everyday family life.

Method: A qualitative phenomenological interview study using a reflective lifeworld research approach. Interviews with 15 parents of otherwise healthy children aged 1–14 years affected by FC.

Findings: Shame is the driving force making parents put everyday life on hold. The quest for control, self-imposed loneliness, guilt, inadequacy, and frustrating battles become essential parts of everyday life to protect it from FC-related shame.

Conclusion: FC has as great an impact on everyday life as any childhood illness. Every part of family life is affected by FC. Continuously family support and guidance are needed.

Practice implications: Healthcare professionals need to take FC more seriously, listen to the parents and try to understand their experiences of everyday life to enable custom made care plans with the family-unit in focus. Care with clinical sensitivity might help parents deal with the attendant shame and stigmatization that stem from illness beliefs about FC.

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Background

Childhood functional constipation (FC) is a condition with no underlying medical, genetic, anatomic, or physiological causes. Inaccurate muscular and habitual conduct results in a retained stool, which causes pain and fear of emptying the bowel, leading to the evacuation dysfunction described in the Rome IV diagnostic criteria (Benninga et al., 2016; Hyams et al., 2016). FC is the most common childhood constipation form, affecting 17% of healthy children in Sweden (Lindgren et al., 2018) and at least 1 in 10 internationally (Koppen, Vriesman, Saps, et al., 2018). Common FC symptoms are straining, the sensation of incomplete defecation, loss of stool or gas accompanied by abdominal bloating and pain (Timmerman et al., 2021). International guidelines (Bardisa-Ezcurra et al., 2010; Koppen et al., 2016; Koppen, Vriesman, Tabbers, et al., 2018) indicate that the gold standard treatment is family

lifestyle adjustments combined with pharmacological interventions. Rectal enemas and oral polyethylene glycol (PEG) are recommended for fecal disimpaction and maintenance therapy (Vriesman et al., 2020).

The onset of childhood FC frequently occurs during infancy and affects the entire family unit (van den Berg et al., 2006). The self-management burden on parents is significant and some parents testify that situations of forced treatment border on feeling abusive. Therefore, continuous guidance and support are needed to enable parents to make well informed decisions about treatment (Flanckegård et al., 2020). Families dealing with childhood FC experience effects on everyday family life that cause suffering (Thompson, Wine, et al., 2021) with implications on issues from daily activities to fundamental life values (Svenaesus, 2014). The extent of suffering is determined by the meaning the illness has for the person, not the illness itself (Cassel, 1982). An illness experience affirms, challenges or changes core beliefs when a family is affected (Kioko & Requena Meana, 2020). Previous research shows that core parental beliefs are challenged in FC treatment situations, making parents question their parenting abilities (Flanckegård et al., 2020).

Early diagnosis and appropriate FC treatment are vital (Bongers & Benninga, 2011; Casias & Newton, 2021). As many children carry their defecation disorder into adulthood, FC should be treated promptly at onset (Timmerman et al., 2021). In Sweden, standard treatment is first

Abbreviations: FC, Functional constipation; RLR, Reflective lifeworld research.

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offered at child healthcare centers (CHC). Second-level care is offered at general pediatric outpatient clinics, followed by tertiary pediatric centers if needed. The negative impact FC has on quality of life (Judd-Glossy et al., 2021; Ranasinghe et al., 2017) decreases for children and parents when FC treatment is offered (Erdur & Ayar, 2020; Kaugars et al., 2010).

Research on FC and its impact on everyday family life from a parental perspective is sparse. Better knowledge about the experiences of parents and the impact of FC on family life will help health professionals to better understand and integrate the parent's perspective when determining treatment plans for families affected by childhood FC.

Purpose

The aim of this study was to explore and develop an understanding of parents' experiences of living with a child with functional constipation and its impact on everyday family life.

Design and methods

A phenomenological design with the reflective lifeworld research approach (RLR) developed by Dahlberg et al. (2008) was used. The method originates from Husserl's study of phenomenology. The RLR approach describes phenomena as they are experienced by individuals and the meaning of that experience. The informant's narrative conveys meaning that can be understood as the phenomenon's essence (Dahlberg, 2006). A lifeworld perspective allows the researcher to encounter the informant's lifeworld, a place from where core beliefs originate, from where we understand, experience and express our understanding of the world. It is from within the lifeworld we can understand how experiences are lived, shared, and communicated to others (Dahlberg et al., 2019).

Participants

Eligible participants were Swedish-speaking parents of otherwise healthy children who received combined oral and rectal pharmacological treatment at home for FC within the previous two months. Registered nurses and urotherapists from three different towns in Sweden recruited participants with a purposive sample. Each care advancement level, one CHC, three general pediatric outpatient clinics and one tertiary pediatric center was represented by 4 children each. Five fathers and 10 mothers from 12 families participated. Fourteen of the parents lived in a relationship with the other parent and one parent was separated with shared custody. The participating parents were 29 to 49 years old (md 38 years). Three were on parental leave, 8 worked full-time and the remaining 4 worked part-time. The duration of constipation symptoms for the children ranged between 6 months and 10 years (md 2.6 years) representing all stages of FC manifestations. The children were in different treatment phases from initial disimpaction with daily PEG and rectal enemas for 3–10 days to maintenance therapy with daily PEG combined with occasional rectal enemas, Resulax® or Klyx®. The children were aged between 1 and 14 years (md 5.8 years).

Data generation

Data were generated in accordance with RLR (Dahlberg et al., 2008) between January and May 2019. All interviews were conducted face-to-face with only one informant and the researcher present, either at the informants' homes, at their workplace or at the local hospital, with the time and place decided by the informants. The first author conducted 14 interviews and the last author one. The researchers had no prior relationship with the participants. The informants were encouraged to tell their story and describe important issues from their experiences in their own words. An opening question started the conversations: 'Please describe an ordinary day in relation to your child's constipation'. Fields

covered and presented in this study were: 'The experience of having a child with FC'; 'The impact on family life'; 'How everyday life is affected'. Probing questions were: 'Please deepen that thought'; 'Can you provide an illustration, please?', helping the informants to elaborate and give in-depth answers. This also helped the interviewers to stay open to the true meaning of the shared experiences. The interviews lasted 24–73 min (md 54 min), were digitally recorded and transcribed verbatim. The dataset was rich in descriptive detail, and its essence was presented within 15 interviews.

Ethical considerations

Informed written consent was obtained from all informants. The study was approved by the Regional Ethical Board, Sweden (2018/32931). Conduct and reporting were in accordance with the Declaration of Helsinki (World medical association, 2013) and the Committee on Publications Ethics International Standards for authors (Wager & Kleinert, 2011). The COREQ checklist was used to safeguard explicit reporting (Tong et al., 2007).

Data analysis

The methodological principles of the analysis were grounded in the phenomenological lifeworld approach, RLR (Dahlberg et al., 2008) with no locked steps or pre-planned path to follow. A scientific openness to the phenomenon and the research data with its meaning was adopted in the search for new understandings of the phenomena. The entire dataset was thoroughly read multiple times and questions about meaning were asked concerning what was said, how it was said and what it meant. By reflecting over the emerging understanding and one's own pre-understanding of the phenomenon, new meaning was allowed to arise and be problematized. This was achieved by a scientific interpretational reflective "bridled" attitude (Dahlberg et al., 2008). Keywords was identified by the first author, and attention was directed toward discovering meaningful parts of units and seeing them in the light of the whole material. Examples of early meaning units were time, conflict, relationships, and everyday life. Meaning units were then ordered in clusters that related to each other, forming the constituents that made up the building blocks of the essence. As the pattern of meaning and the text emerged by the hand of the first author, the other authors critically reviewed the findings and gave constructive feedback and input based on the original dataset. A temporary understanding of patterns was discussed, formulated, rewritten, and sharpened multiple times by the research team over several sessions until the whole team agreed on the findings. Reformulation and discovery of new questions along the way kept the essence of the phenomena open until the end of the work. Creating a main interpretation and describing the essence is a clarification of meaning, an explanation of the phenomenon's style. Since the aim was to understand more of parent's experiences, the deeper underlying and intentional meaning of the phenomenon parent's experiences of childhood constipation needed to be found. The constituents were therefore reviewed again, now against each other to embrace similarities. This raised the constituents to a higher level of abstraction where the pattern of and connection between them outlined the essence of the phenomenon (Dahlberg, 2006). The full empirical analysis and its findings were established based solely on the data obtained in the study.

The findings are first presented as the essential structure of meanings, followed by their constituents. The essence is more abstract whereas the constituents show individual variations with all possible nuances that are present in the data. Where the respondents' voices describe meaning nuances in an explicit way, citations from the interviews are presented in the findings (Dahlberg, 2006). The constituents are part of, and relate to, each other, but primarily constitute the essence, describing the full spectrum of meaning. The essence must be seen in every constituent as they give the context to the essence. They are to

be understood as contextual figures against the background of the essential meaning (Dahlberg & Dahlberg, 2019).

Findings

The essential meaning of living with a child affected by FC is grounded in the necessity to relate to shame, a powerful source of priorities that put everyday life on hold. A basic thing like making your child go to the toilet and take care of their bowels becomes the central part of everyday life for parents. *'It is the top priority in our family for the moment'*, one parent states (Informant 8, Father of a girl, 7 years old). The presence of shame is intermittent but common enough to make parents try to shield their children and themselves from it through various actions. The avoidance of shame makes them put everyday life on hold. Family measures are taken to manage the shameful consequences of FC on all levels: in society, in relationships, or of not managing the situation. Even the nature of the topic is associated with shame. It is in the light of shame that putting everyday life on hold can be understood, with shame being the fundamental motivation for the pursuit of control. Parents aspire to plan and protect children from FC-related shame but despair when they fail, which leads to even more shame. Time and activities are prioritized, with FC first and everything else second. Parents express that the culture of everyday family life shifts; nothing is perceived to have changed yet many real changes has been made subconsciously, a habituation of the small changes made over time. The shame-driven measures required by FC consume time and effort as the quest for control, loneliness, guilt, and the frustrating battles all contribute to putting everyday life on hold. All from the nudging of shame.

Constituents

One step ahead to regain control

Much is put on hold to make everyday life work as smoothly as possible despite FC. To regain control, parents try to stay one step ahead by making plans to avoid shameful toilet accidents. They try to predict what medications, clothes or hygiene products might be needed during the coming day, trip, or activities. Parents find that living with a child affected by FC requires cyclic structure and routines; *'it is like living with a timer'*, one parent said (Informant 10, Father of a girl, 3 years old). When parents refer to FC and the effect it has on their child and family life, they say that everyday life is divided into fractions of hours, days, weeks, years, or part of a lifetime. Parents live by bowel intervals, where every bowel movement grants a small space of time to relax, counting down the days until the next episode of treatment or bowel emptying is upon them. Parents are uptight and become exhausted through never being able to let go.

'It is hard, we have to think about it 24/7.' (Informant 1, Mother of a boy, 2 years old).

The unpredictability of FC makes the world revolve around bathroom habits, toileting, medication, food, fecal leakage, bowel movements and constant planning to prevent, adapt and adjust in daily life. The endeavor to be one step ahead permeates every waking hour, a concern that makes families live one day or week at a time. Other plans are put on hold or leisure time activities are delayed.

'We had to leave [the party] to go home for her to be able to have her bowel movement. Then she got calm. It doesn't affect our family life that much but, in some ways, you can't go away just as much.' (Informant 9, Mother of a girl, 3 years old).

Knowing this, parents avoid long-range plans to travel or go to playgrounds, knowing inevitable FC incidents can occur at any time. Awareness of facility locations is essential. Some children avoid toilet visits during school hours, which worsens the risk of fecal accidents. To regain

control, there are meetings at school to make contingency plans for fecal incontinence episodes. Parents adjust working hours to accommodate the length of school days to decrease the impact of FC consequences on the child, which influence a parent's work and income.

The planning and the prepping to remain one step ahead are automated into a routine that works without reflection. Small insignificant changes added to other small adjustments go unnoticed over time. The notion that nothing has changed emerges despite all the measures that have been taken in everyday life. This ever-present maneuvering of the situation shapes the life of the family until the default mode is 'adjustment'. Putting things on hold and consciously missing out on other things give parents greater control. They find this approach helps them stay one step ahead in handling or avoiding shameful FC consequences. With good planning almost everything can be accomplished, or every event can be participated in. The one-step ahead tactic contributes to making FC a normal part of life, that does not limit the family in any way, except the need to remember to always pack a change of clothing.

Self-imposed loneliness

Parents describe a sense of loneliness, often self-imposed, in everyday life situations because of FC and the priorities that have to be made. Parents find FC socially minimizing because they need to put activities aside. Repeatedly canceling plans with friends makes social life lonesome and desolate, with an expressed fear of not connecting again.

'You don't have the strength to struggle both at home in the family and have time for a full-time job in addition to being nice and social, at least I cannot manage all that. So, you start to shield yourself by just staying within the family without inviting people over at weekends. You don't have the strength to plan; you just take one day at a time.' (Informant 12, Mother of a boy, 12 years old).

At times families must leave events early because of FC. This self-imposed isolation results in absenteeism from school, work, and social opportunities. Parents find that FC symptoms limit the children, leading to poor self-esteem and affecting them academically. Therefore, knowing the adjustments will cause the family or child to miss out on something, it takes an effort to stick with them. Parents pity their children because of their limited social interactions. Non the less, they often consider increasing their social limitations to avoid bullying by friends.

'It's a worry not to be able to find friends or not being able to function socially at school [in the future] because of bullying, because it is not socially acceptable to poop on yourself when you are ten years old.' (Informant 8, Father of a girl, 7 years old).

In the quest for socially acceptable toilet and bowel behaviors, parents feel left alone. Society appears not to understand the daily challenges FC brings. Parents wish to belong in a context where others can relate to the constant planning, reminders, negotiations, and conflicts, with occasional lies and reprimands. FC is difficult to talk about as parents find it socially taboo with a stigma attached to the subject. Discussing bowel habits and incontinence feels socially inappropriate, which makes parents feel isolated.

'That's how it is, some diseases are easier to talk about, and some you don't want to talk about [...] this one you hardly mention, no. Even if we live in the 21st century, it can be taboo.' (Informant 15, Mother of a girl, 14 years old).

Parents long for contact with someone else outside their inner circle with whom to share the struggle, another family with similar experiences. Some parents feel the sense of loneliness is reduced when reaffirmed by healthcare personnel and with improved knowledge. Some families find that a clear and inviting communication path to healthcare make life easier. At the same time parents experience a loss

of independence as a family when they need to rely on help from others. Parents feel that no one else, not even the extended family, understands the complex reality and the loss of normality that childhood FC entails. To ease that lonely feeling some parents form a parental team to encourage each other and make an alliance with the child through treatment. This enhances the child-parent relationship as well as easing the sense of loneliness.

Guilt and inadequacy

For many parents, childhood FC is initially considered a normal phase that will pass. The insight that home remedies or time is not a sufficient solution comes with guilt and frustration. Parents see a symptomatic progress they missed and believe they have failed as parents.

'In retrospect we understand it has been going on for a long time, but we tried for a while to think of it as normal, that children can get a bit constipated.' (Informant 2, Mother of a girl, 2 years old).

With deterioration over time, parents add adjustments in everyday life to gain control, which leads them to adopt the principle of keeping one step ahead. Friends and family get low priority as constant planning and focus on the child's needs consume time and strength. Siblings must take a back seat as the child with FC requires more attention or help. Parents feel inadequate in relation to time, effort, and engagement. Other people are put on hold at the expense of relationships. The impulse to start conversations about bowel movements makes parents sad and guilty about prioritizing FC over other content in everyday life.

This constant focus tends to overshadow the fun and pleasant moments parents share with their child. They feel the development of their child's autonomy is delayed by their persistent monitoring. They would like to focus on something other than FC, such as what the child has crafted in preschool or who he/she played with that day. Instead, they find themselves asking and wondering about bowel movements. Forgetting or missing the planned measures is a worry, and when it happens parents feel guilty because they were not prepared enough.

'You have to be the one who continuously reminds him...now we have to go to the bathroom. And sometimes you might forget; then disaster strikes' (Informant 11, Mother of a boy, 7 years old).

Parents blame themselves for not always managing things optimally. A sense of being overwhelmed by the situation rather than advocating for their child in a focused manner emerges. Some parents become resigned and go into survival mode. They shut down their feelings and merely do what needs to be done without reflection. Failing their parental responsibilities when FC priorities have direct consequences on family life brings guilt. Their inability to prevent or overcome FC is a reminder of their self-perceived inadequacy as parents.

'What else can we do, are we missing something, have we done something wrong in the past which has led to this?' (Informant 2, Mother of a boy, 2 years old).

To ease the guilt created by their inadequacy, parents work even harder to stay one step ahead, providing more reminders, planning and restrictions to avoid toilet-related accidents. They adapt the food they serve, which limits variety and can lead to conflict. Furthermore, giving treats or sweet drinks every day to enable medication violates their parental principles, while failing to respect the child's view in treatment situations gives a bad conscience. Parents are ashamed of their child because of leakage or behavior resulting from FC. They feel skeptical about their children's lack of awareness of the situation or lack of willingness to cooperate. The constant monitoring and lack of confidence in the child's ability to manage independently create feelings of guilt. Parents are aware that children of school age are expected to be fully toilet-trained.

'She doesn't care about her soiling. It smells and it's really difficult to know what to do. You worry about when she is away playing with friends.' (Informant 4, Mother of a girl, 8 years old).

Unsuccessful training in cleanliness results in feelings of failure and shame, with the lack of progress causing frustration, resulting in putting everything else in life on hold.

Frustrating everyday battles

Parents find that living with a child affected by FC brings different aspects of battles into everyday life. Fights *about* the child, *with* the child and *for* the child are frustrating and put life on hold. To protect themselves from shame and stigma, they become the frustrated and difficult parent who battles and advocates for their child. Parents feel that being troublesome in different settings becomes a necessity because of FC.

Examples of battle between parent and child are forced medication and constant reminders about toilet habits; battle between spouses tends to be frustration about long treatment time and lack of control. The situation triggers the worst in angry parents, testing their patience to the limit and easily escalates into conflicts. Parents talk about children who lie out of shame and hide dirty underwear to escape blame or reprimands. They also express concern about damaging their relationship with the child due to the nagging, reminders, negotiations, constraints, and bribes related to bowel movements and toilet habits.

Battles also occur between school or preschool representatives and parents about support and management during school hours. The good will of external adult support, i.e., wanting to become partners in helping the child is important to parents.

'We had a meeting at school because of his frequent absenteeism and we concluded that some of it originated in his urgency and the insecurity about instant access to clean toilets. [...] So, he was assigned another toilet at school which has worked out.' (Informant 13, Father of a boy, 12 years old).

Cooperation with school decreases absenteeism, according to parents, and reduces the risk of bullying related to FC symptoms. It helps parents to stay one step ahead, which increases parental satisfaction.

Aspects of everyday battles include interaction with the healthcare system, with disappointment or distrust when parents feel overlooked. Situations where the same treatment advice is delivered repeatedly despite the parent's declaration of lack of improvement.

'I can feel frustration over the fact that we have had the same treatment regimen since she was three years old. It just goes on, we meet someone and talk, some nurse who says it's important to go to the toilet regularly... well, she already knows that, but it simply does no good.' (Informant 7, Mother of a girl, 7 years old).

Resigned, and a little offended, many families treat FC despite their skepticism. Expecting the same advice, and too frustrated to battle, they abstain from seeking care at the next setback. The ignorance, knowledge deficit and slow response from parts of the healthcare system astound parents. The main responsibility for locating the right care falls on parents. One example of how difficult that responsibility can be, is when combined physical and psychological FC symptoms occur, with the need of support from different departments. Some become warriors, working their way up through healthcare levels and alternative providers, whereas others get stuck, trusting what they are told, or simply give up. This evokes anger, unsureness of themselves and exasperation. They lack faith in the system and lose the strength to battle.

The lack of a clear cause of FC makes some parents blame and question themselves. To ease the guilt a frantic search for an explanation begins. They feel they have to fight the system for answers.

'We have tried for a long time since she was small, but we didn't get any help because she was supposed to grow out of it.' (Informant 14, Father of a girl, 9 years old).

On reflection, parents say that the search itself alters the situation and the treatment. Increased knowledge and experience of FC transforms the situation from tough to comprehensible, even normal, over time. A sense emerges that nothing in life has changed, yet the battles they have fought have conditioned their worldview. One parent state *'Eventually you get used to it.'* (Informant 6, Mother of a boy, 2 years old) When follow-ups, new suggestions and an action plan are offered, parents feel more secure and need to battle less.

Discussion

The aim of this study was to explore and develop an understanding of parents' experiences of living with a child with functional constipation and its impact on everyday family life. The main finding is 'everyday life on hold', as an expression of the impact FC has on everyday family life. One explanation to this finding is that other things, activities, persons, and relationships must stand back and be put on hold because of FC or FC-related consequences. Sometimes because time is limited, other times because of priorities or choices. We propose that the reason to all the endeavours described in our study originates from something else than a busy lifestyle or the ordinary reality of being a parent. That 'something' can be explained by shame. Shame as the motivating factor to priorities and choices, the nudging that make parents engage in protecting their child and themselves from shameful consequences of FC. The actual word shame was not prominent in the interviews but sifted through many conversations on all different levels from within self to society.

Shame is defined as a negative emotion with self-evaluation revealing a discrepancy between one's actual self and ideal self (Miceli & Castelfranchi, 2018). Shame focuses on character rather than behavior and causes self-consciousness and self-judgment. Modes of expressions include feelings of being no good, inadequate, and unworthy, with a lack of efficacy and loss of control. Shame causes individuals to imagine that they are viewed negatively by others, and the fear of a public shortcoming evokes the desire to hide. (Behrendt & Ben-Ari, 2012; Blum, 2008; Scheff, 2013; Tangney & Salovey, 1999). This short summary of shame and its characteristics is reflected throughout many parts of our findings and serves as a horizon for the following discussion. Every parent needs to relate to some level of shame as FC is associated with taboo and stigma within the self and in society. Parents in this study hesitate to share their situation in public because of the nature of the topic. A population survey shows that almost 50% of adults never discuss their bowel problems with anyone due to embarrassment (Meinds et al., 2017).

The need to regain lost control through meticulous planning and keeping one step ahead is partly a reflection of shame. Practical planning is a concrete and simple way for parents to influence their own reality. Though unable to control the actual FC, they aspire to control the consequences of FC. Our findings indicate that the longer the duration of symptoms, the more adjustments were made in everyday life to compensate. To spare families this struggle, it is important to offer regular follow-up to children presenting with FC as no one can predict which child will have remaining symptoms into adulthood (van Ginkel et al., 2003).

The self-imposed loneliness described in our findings touches on the fear of public shortcomings coupled with the desire to hide (Blum, 2008). Social interactions on all levels are influenced by priorities made because of FC. Parents brace themselves to stay ahead and to endure the isolating consequences the adjustments cause. Another study shows that childhood FC taboos led to feelings of isolation in parents (Thompson, MacDonald, et al., 2021). In our study, children are kept

away from playdates and parents restrict their own personal leisure time activities with friends, a manifestation of protective shielding.

Feelings of guilt and inadequacy are other findings in our study with the presence of self-judgment as a reflection of shame (Blum, 2008). Parents express guilt over the lack of guidance and prevention they can offer their child. Some parents even blame FC problems on themselves as failures in their child-rearing efforts. Guilt and shame are closely connected yet differ. Shame originates from the lack of power to meet the standards of one's ideal self (character), whereas guilt is caused by violation of the standards of one's moral self (behavior) (Miceli & Castelfranchi, 2018). The parents' perceived inability to meet the expectations of self or others is an example of violation of core beliefs about how they wish to act. Disappointment at their performance as parents is expressed by some parents as inadequate disposition of time and effort toward others, which induces guilt.

Parents in our study turned to healthcare rather late, indicating a lack of initial knowledge or insight that FC might need medical attention. At the same time experiences of being dismissed or not taken seriously when seeking healthcare related to FC are described, which concur with other findings (Thompson, MacDonald, et al., 2021; Thompson, Wine, et al., 2021). This, together with a long timeline from start to diagnosis, suggests a struggle to find the right approach to FC. Wright & Bell state that it is not the illness itself that causes suffering but rather beliefs about the illness (Wright & Bell, 2009). Illness beliefs are significant cornerstones that shape the way families cope with illness and family identity (Bell & Wright, 2015). Beliefs about FC being a condition (that a child will grow out of) but not an illness (in need of care) might explain the discord in our findings. It raises the issue of the justification for a) healthcare providers to propose treatment to uninformed parents and b) parents to battle for adequate missing healthcare. Not knowing who the 25% (Timmerman et al., 2021) are who will have remaining FC symptoms into adulthood is reason enough to both fight for, or prompt, treatment for every child for a successful treatment outcome (Casias & Newton, 2021). Finding a healthier approach to core beliefs about FC can soften the suffering.

The similarities between the effect of FC in our findings and other childhood illnesses such as cerebral palsy, multiple sclerosis, epilepsy, type 1 diabetes, asthma, juvenile chronic arthritis, complex health needs (Nygard & Clancy, 2018) are striking. Parents' experiences of home care for children with special healthcare needs of any kind seem to be independent of diagnosis in terms of worries, suffering and struggle. Never letting go, using war metaphors and feeling mistrusted seem to be generic. Moreover, they describe always carrying the concern of the child in the back of their mind, constant planning and trying to keep everything as normal as possible. Other areas of similarities between our current study and other diagnoses include finding it a battle to navigate the healthcare system while being ignored or mistrusted, or the lonely feelings of guilt and shame through dealing with taboos and isolation (Nygard & Clancy, 2018). Specific studies on FC experiences point to similar feelings of guilt and shame (Thompson, Wine, et al., 2021) and the feeling of doubt and of questioning their capabilities as parents (Flanckegård et al., 2020). This, in combination with the present findings, implies that FC is as impactful as other long-term childhood conditions on parenthood and family life. Families with childhood FC suffer in the same way as other families and should therefore be treated equally. Understanding of the similarities of experiences is important. With this knowledge, healthcare professionals can gain a deeper understanding of FC and improve clinical practice. They might better support families and enable the best aspects of the family unit to flourish despite FC.

Practice implications

Since the experience of FC can be compared to experiences from other childhood diagnoses, childhood FC and the associated feelings of

children and parents need to be taken seriously from early onset. Healthcare professionals need to seek and understand parents' experiences of everyday life to grasp beliefs and emotions related to FC. This can be done by showing interest and listen to the children and their parent's stories and experiences, learn from them and act accordingly. With a better understanding of families underlying illness beliefs, specific needs can be met with an inclusive professionalism. This consists of a professional family-centered caring style with a greater clinical sensitivity, enabling custom made care plans to buffer suffering in the family. The reported shame, guilt, and feelings of inadequacy in parents could be mitigated, making everyday life a better place for families affected by childhood FC.

Limitations

There are strengths and limitations with the RLR-approach. A more interpretive method like Hermeneutics could have deepened some parts of the analysis, especially in relation to shame. On the other hand, RLR enables the possibility to stay close to the interviews and the narratives of the informants. One strength with the RLR-approach is that due to the "bridling" attitude, the analysis is not influenced too early in the process by the researchers' preunderstanding of the phenomenon. This keeps the analysis open until the phenomenon 'presents itself' and the essential meaning of living with a child affected by FC become clear. The research group had a considerable preunderstanding of the phenomenon through many years of clinical experience within pediatrics, mental health, and FC, as well as within the research method. Therefore the "bridled" (Dahlberg et al., 2008) reflective and open approach was adopted throughout the process. Focus was to ensure the analysis was true to the interview text so as not to affect the findings. No dominant theoretical pretext colored the phenomena-oriented conduct during interviews and analysis. With another method or approach requiring the researchers to strictly follow the outlined analysis steps, another result might have emerged.

The participants were eager to share their experiences, which indicates that the study is relevant and underlines the importance of bringing their voices into research. The use of personal quotes strengthens the study as they aspire to evoke images and feelings the reader can relate to, making the phenomena visible in the reader's lifeworld.

The diversity of the informants and their children is a strength in the study. The different stages of FC, the varied duration of symptoms from three different care levels, along with the representation of both mothers and fathers provides great variation in the material. A limitation is that all participants had to understand and speak Swedish. The age range of the children, between 1 and 14 years, might also be problematic. In one respect the findings show the trajectory of experiences over time, a progress of approaches to FC as time passes. However, the equalization of experiences from the different stages of childhood might take the generalization too far. Another limitation might be that most of the parents were living together in a two-adult household, which might not be representative of every society.

Our findings are the result of systematic work, but ours is not the only possible interpretation. The findings apply to Swedish conditions and cannot be transferred to other contexts with different healthcare settings and laws. Nevertheless, this study may have relevance for other healthcare providers and parents because FC symptoms are universal. The purposive sample of participants may have been biased as the nurses and urotherapists may have invited patients who demanded their attention during the inclusion period. Therefore, our findings run the risk of representing the experiences of more severe cases of FC or families who are inclined to seek help. Mitigating this risk is the equal inclusion of children from different care levels, each representing 1/3 of the study population. The clinical experience of the first author asserts that many families manage FC and FC treatment without major issues. With that in mind, other less intrusive perspectives on FC might not be visible in our current findings. Nonetheless, our findings show

that FC has the potential to evoke feelings and experiences described in other childhood illnesses.

Conclusions

The shame-driven measures taken in everyday life affect every part of family life. Families struggling with childhood FC seem to be just as affected as families dealing with other childhood illnesses. They are just as much in need of family support and guidance during assessment, treatment, and follow-up.

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CRedit authorship contribution statement

Gunilla Flanckegård: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Project administration, Funding acquisition. **Evalotte Mörelius:** Conceptualization, Methodology, Writing – review & editing, Supervision. **Patrik Rytterström:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare that there is no conflict of interest.

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