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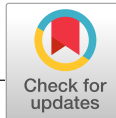
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Experiences of parents who give pharmacological treatment to children with functional constipation at home

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Abstract

Aim: The aim was to explore the lived experiences of parents who give oral and rectal pharmacological treatment to their children with functional constipation at home.

Design: A phenomenological design with a reflective lifeworld research approach that describes phenomena as they are experienced by individuals.

Methods: From January–May 2019, 15 interviews were conducted with parents of children with functional constipation with home-based oral and rectal treatment. Parents were recruited from three different healthcare levels. Open-ended questions were used starting from the description of a normal day with constipation treatment. Analyses were made with an open and reflective 'bridling' attitude.

Findings: Constipation treatment causes parents to question their parental identity and what it means to be a good parent. Forced treatment makes them feel abusive and acting against their will as parents. There is a conflict between doubt and second thoughts about the treatment, the urge to treat based on the child's needs and encouragement from healthcare professionals to give treatment.

Conclusion: As pharmacological constipation treatment can be experienced as challenging, it is important to help parents make an informed decision about how such treatment should be carried out at home. The findings reveal a medical treatment situation where parents hesitate and children resist, resulting in insecure parents who question their parental identity.

Impact: The findings point to the importance of supporting parents in treatment situations. Healthcare providers need to treat children with constipation with greater focus and more prompt management to prevent these families from lingering longer than necessary in the healthcare system.

KEYWORDS

children, functional constipation, good-parent beliefs, lived experiences, nursing, parental identity, phenomenology, treatment

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1 | INTRODUCTION

Elimination difficulties such as constipation are important and need to be addressed with sensitivity and dignity. Since it is such a private act for most people, its care requires empathy, knowledge and skilled nursing input (Pellatt, 2007). Childhood constipation is an issue for parents and healthcare workers worldwide and the relevance of the topic is both national and international.

The international standard treatment for childhood constipation is the restoration of bowel habits and toilet routines, evacuation of the bowel and maintenance treatment. The treatment is often carried out at home by parents, but adherence to treatment may be poor due to difficulties in implementing the treatment plan (Bongers, van Wijk, Reitsma, & Benninga, 2010; Tabbers et al., 2014). Studies on lived experiences of constipation treatment of children at home are scarce. To our knowledge no study has previously focused on parents' experiences of treating children with functional constipation at home.

1.1 | Background

Functional constipation is a common worldwide problem, with no gender differences and with prevalence rates up to 32% in infants and young children (Koppen, Vriesman, et al., 2018). In Sweden the incidence of constipation in healthy children is 17% and 55% of children with constipation are not treated (Lindgren, Nejstgaard, Salö, & Stenström, 2018). Functional constipation is described and defined in the ROME IV criteria (Hyams et al., 2016) where 'functional' means otherwise healthy. The underlying mechanism is most likely a withholding behaviour due to pain or social reasons (Mugie, Di Lorenzo, & Benninga, 2011). Evacuation difficulties and stool retention with loss of rectal sensation, faecal incontinence, abdominal distension and painful defecation are common symptoms (Zeevenhooven, Koppen, & Benninga, 2017).

Constipation is treated by nonpharmacological and pharmacological means. Educating the parents and toilet training the children with behavioural interventions are accompanied by rectal enema and/or oral polyethylene glycol (PEG) (Koppen et al., 2016). The oral treatment (PEG) is a powder dissolved in one glass of liquid to drink daily. The rectal treatment is a liquid administered rectally through a thin plastic tube as an enema. Disimpaction for 3–10 days with high dose oral and/or rectal laxatives as a combination therapy is the first-line treatment as faecal impaction occurs in 30–75% of patients with functional constipation (Bekkali et al., 2009; Yoo & Bae, 2017). The maintenance phase continues until all symptoms are resolved and regular bowel habits are established, the time varying from weeks to years (Bardisa-Ezcurra, Ullman, & Gordon, 2010; Tabbers, Boluyt, Berger, & Benninga, 2011).

Approximately 60% of children are successfully treated in one year, but 50% of these have at least one relapse within the following 5 years (van Ginkel et al., 2003). The long-term prognosis is negatively affected by treatment delay, older age at onset and low defecation frequency.

Persistent symptoms into adulthood affect approximately 25% of children with childhood constipation and poor adherence to treatment is seen in two-thirds of the children after 6 months of treatment (Bongers & Benninga, 2011). Because of the inconvenience of taking the medicine and treatment dissatisfaction, only 37% of constipated children adhered to the oral laxative treatment (Koppen, van Wassenae et al., 2018). Active parents managing daily treatments and supporting adequate toilet behaviour achieve better treatment success in the short term. Thus, self-management behaviour is an important factor for success (Modin, Walsted, Rittig, Hansen, & Jakobsen, 2016).

Continuing chronic constipation may affect psychosocial development, causing emotional, physical and social impairment. Children experience distress, which affects self-esteem, relationships and success in school (Bongers et al., 2011; Lisboa et al., 2008). Health-related quality of life (HRQoL) scores are lower than in healthy controls, indicating the negative impact constipation has on children (Vriesman et al., 2019). Parents rate HRQoL scores for their children lower than the children themselves do. This may be because there is often a degree of denial amongst children and the responsibility for adhering to treatment falls on the parents (Youssef, Langseder, Verga, Mones, & Rosh, 2005).

Childhood constipation and the struggle to make treatment work is challenging for parents (Kaugars et al., 2010). Making informed unselfish decisions in the best interest of the child, preventing suffering, meeting the child's basic needs and advocating for the child are examples of good-parent traits or beliefs when caring for an ill child (Hinds et al., 2009; Maurer et al., 2010). These good-parent beliefs shape how parents individually perceive and fulfil their duties to their child and for many parents are the basis for figuring out what parenthood is (Feudtner et al., 2015).

Parents sometimes need to give children medical treatment at home, occasionally in a forceful manner. We wanted to explore the lived experiences of giving pharmacological childhood constipation treatment at home to better understand the situation parents face when following healthcare recommendations.

2 | THE STUDY

2.1 | Aims

The aim of this study was to explore the lived experiences of parents who give oral and rectal pharmacological treatment to their children with functional constipation at home.

2.2 | Design

A phenomenological design with a reflective lifeworld research approach (RLR) developed by Dahlberg, Dahlberg, and Nyström (2008) was used. The RLR approach is phenomena-oriented and based on the philosophies of Husserl and Merleau-Ponty. It describes phenomena as they are experienced by individuals without a dominant

theoretical pretext, in this instance the meaning of lived experiences of giving pharmacological constipation treatment to children at home. The interviews and the analysis were conducted with a 'bridled', reflective and open approach, not making assumptions based on any pre-understanding.

2.3 | Participants

Children in Sweden are offered free health care and medications, offered through local children's healthcare centres (CHC), where functional constipation is usually first acknowledged and treated. If the treatment given by nurses in collaboration with general practitioners is not enough, referrals are made to general paediatric outpatient clinics and further on to tertiary paediatric centres when required. Parents of otherwise healthy children aged 1–18 years who received oral and rectal pharmacological treatment for functional constipation were invited to participate. Participants were recruited by nurses and urotherapists from all the above-mentioned care levels with a purposive sample in the inclusion criteria. Five fathers and 10 mothers participated (Table 1).

2.4 | Data generation

Data were generated between January and May 2019. An interview guide was used with the opening question: 'Please describe an ordinary day in relation to your child's constipation'. Fields covered and presented in this study were 'The experience of conducting the treatment at home' and 'Thoughts and feelings about the treatment'. Probing questions included: 'Please elaborate that

thought. 'Can you give an example, please?' The researchers had no prior relationship with the participants. The time and place for the meetings were decided by the informants. All interviews were conducted individually, either at the informants' homes, at their workplace or in a quiet room at the local hospital. The data had a descriptive richness resulting in a good variation representing the phenomenon after 15 interviews. All interviews were performed, audio recorded and transcribed verbatim by the first author except one that was made by the last author. The first interview, a pilot, was later incorporated in the analysis after being audited by a second author.

2.5 | Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki (2013) and approved by the Regional Ethical Board (2018/329-31). Informed written consent was obtained from all informants, who were informed that participation was voluntary and withdrawal possible at any point without any effect on their child's care.

2.6 | Data analysis

Data were analysed according to RLR principles. The material was read openly by multiple authors to get a sense of the whole. Meaning units were identified and ordered in clusters that were related to each other and formed a pattern that was discussed in the research team. The structure emerging from the data began to shed light on the meaning of the phenomena, resulting in three constituents that together composed the essence of the phenomena. The interviews

TABLE 1 Details of participants

Interview	Interview time in minutes	Parent age in years	Child age in years	Duration of constipation period in years
1	73	34	2	1
2	54	36	2	0.5
3	47	38	1.5	1
4	52	45	8	4
5	59	29	2.5	1.5
6	24	29	2	1.5
7	50	38	7	4
8	59	41		
9	63	31	3	0.5
10	38	35		
11	61	39	7	5
12	54	40	12	1
13	55	46		
14	39	41	9	7
15	36	49	14	10
	Md 51	Md 38	Md 6	Md 3

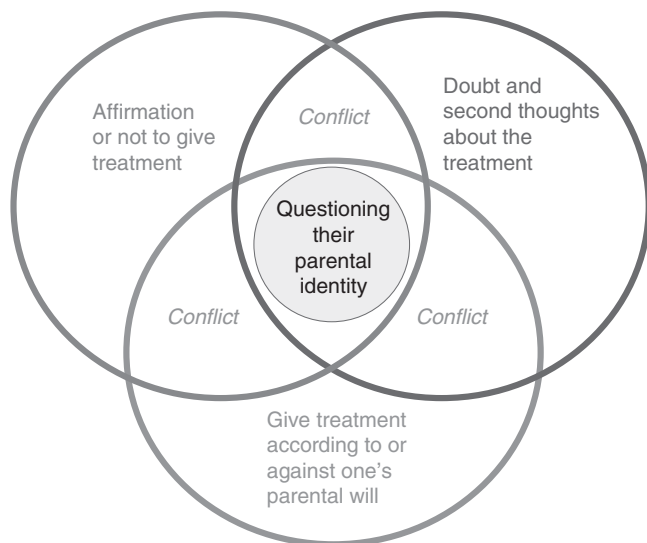


FIGURE 1 The essence and constituents of parents' experiences of child constipation treatment at home

were then read again as a whole to form a background to the new parts. The process of RLR is a balance between free discovery and scientific guidelines; it does not follow any pre-planned path. Hence the names of the constituents and the formulation of the essence of the phenomena were kept open until the end. It is essential not to make decisions too soon to ensure an open and reflective attitude and prevent individual pre-understanding from influencing decision-making. The final terms represent the new understanding of the meaning of the lived experiences and describe the essence of the phenomena.

2.7 | Rigour

Phenomenological research acknowledges that the researcher understands and has a relation to the phenomenon in focus. To be objective as a researcher means 'bridling' one's pre-understanding throughout the research process and being aware of the impact pre-understanding has on how we understand phenomena (Dahlberg et al., 2008). By adopting a questioning attitude and not taking any understanding for granted, 'blind spots' were identified and conclusions were questioned in the research team (Dahlberg & Dahlberg, 2020; Van Wijngaarden, Van Der Meide, & Dahlberg, 2017). Furthermore, there was a wealth of variations among the participants in age, gender and advancement in care and duration of symptoms, which strengthens the study. Expressive qualities, such as emotions or uncertainty that permeate the content of the conversations were noted in the transcriptions to strengthen understanding of their meaning. Trustworthiness was obtained using quotations from the interviews to ensure the result remained close to the data. The analysis has been verified by multiple authors. The COREQ checklist was used to safeguard explicit and comprehensive reporting (Tong, Sainsbury, & Craig, 2007).

2.8 | Findings

The findings are first presented as the essential structure of meanings, followed by their constituents. The essence of the lived experiences of giving children pharmacological constipation treatment at home is a conflict between affirmation and doubt about the act of giving treatment. This conflict obliges parents to choose whether to give treatment, according to or against their own understanding of what it means to be a good parent, making them question their parental identity (Figure 1). The thoughts and moral compass they had as cornerstones in parenting are re-examined. As every chosen action has a consequence that reflects on the parents, deciding what is best for the child can be challenging. There is a palpable conflict between following prescriptions from an authority, the healthcare system, to show that you can perform and manage as a parent and the intense doubt about whether it is the best thing for the child. Contradictory feelings leave parents in the precarious situation of being thrown between emotions and facts. Giving constipation treatment at home creates feelings of having multiple personalities that are morphing dynamically between the loving, nurturing character that gives comfort and the firm, evil character that is hurting the child. There is a feeling of being a little bit of everything at the same time with all characters intertwined. Ultimately it comes down to whether to execute the treatment or not. Sometimes doubt will win and treatment stops. Other times, parents accept the situation and carry on, disregarding their own feelings by doing the best they can for their children. This causes parents to question their identity as a parent; 'Who am I when I do this'?

2.9 | Give treatment according to or against one's parental will

In treating constipation at home, some parents question the way they act. It might be the first time they inflict something unpleasant in their child and are unsure what is acceptable in the role of parenting. Their own beliefs about how a good parent should act are challenged. Looking at the treatment options they have, they evaluate themselves and the responsibilities that come with parenthood:

...we have another type of relationship and then sometimes we suddenly do something that causes him pain, it doesn't fit well with what it is usually like (Mother of a boy, 2.5 years old).

Purposely inflicting bodily pain to achieve long-term results is not always easy even if it is for a good cause and in the best interest of the child. It violates parent's own identity as loving and nurturing. One informant said that making better long-term decisions even though the child suffers at the time can be frustrating but is what parenting is all about, to not take the easy way out. Feelings of worthlessness and

failure are expressed by insecure and discouraged parents, who question their own value. Doing something 'bad' is in clear contrast to what parents want. The feeling of being the 'evil one' and not respecting a 'No' from their child tears apart their self-image of being a protective parent. It is a terrifying insight to realize that the child connects pain and discomfort to them as parents and does not understand that it is meant to help. They want to comfort and soothe their child, but paradoxically must handle the discomfort they feel they have inflicted on the child:

To see your child feel bad and know that we have caused it and he does not understand why we have done it./.../ ...and the fact that we are the ones who have done this and he only sees that we are doing something that makes him feel bad, the fact that he connects it to us... (Mother of a boy, 2.5 years old).

This insight is followed by fear that the child will link that experience to the parents and turn on them. They worry about long-term effects and how their relationship will develop with eroded trust as a result. Their concern that the experience will leave deep subconscious scars that will last forever results in thoughts such as 'what have I done to my child'. They express bad self-conscience and a fear of drowning in the bad experiences:

Everything that is nice and good is going to drown in the sheer volume of conflict and arguments and taking care of thousands of clothes with poop all over them over several years. And the fights about going to the toilet and... that's what sticks in the memory, things that happen over and over every day. And then all the good moments we have... will we be able to sort them out? (Father of a girl, 7 years old).

Forcing treatment on children in the safe environment at home changes the balance of the location that is supposed to be the most secure place for them. As a result, parents experience treatment given at home as an act that goes against their own will.

2.10 | Doubt and second thoughts about treatment

Doubts and second thoughts are common, with reservations about the treatment and the advice received. Parents question the cause of the symptoms or ask whether there is an alternative treatment. Poor treatment results and increasing resistance from the child along with the experience of overruling the child's wishes make parents think again. Urging the child to drink the oral treatment, sometimes lying about what is in it or bribing them with money or candy are examples of actions that parents' later question or regret:

The powder was not so difficult to administer, you only had to mix it with a little liquid./.../ He got the

taste even though I mixed it with juice, so it has always been a struggle to get him to drink it. (Mother of a boy, 2 years old).

When the toddler or adolescent does not want the medical treatment, but parents give it anyway, they exclude the child from the decision-making. Parents doubt their own ability to perform and feel they need to be harsh with their children, bordering on violence when they restrain and hold them firmly when giving the medication. They feel cruel because they use more strength than they would like to, although their intent is not to hurt:

Holding your child firmly to be able to do something that is so intimate feels terrible. It does not feel quite right having to do it. Even if you know it's for a good reason. (Mother of a girl, 2 years old).

Concerning rectal treatment with enemas, several parents end up with a feeling of and comparison with, an abuse. They have strong second thoughts about enforcing treatment when the children refuse, feeling bad and that they are violating their child when they reflect and see the situation through their children's eyes:

...the feeling now when I use the word 'abuse' is the fact that she felt we were hurting her, that we were doing something against her will and her body. And then the situation becomes even more difficult when it concerns her intimate parts and you really have to hold her arms and legs firmly, while someone else, from her point of view, is hurting her. And she screams "no" and "stop" and you still carry on; it feels like abuse even though I know it is not, but it feels like it and that's why I stopped [giving the treatment]. (Mother of a girl, 3 years old).

The comparison is made to other unpopular actions for small children or other medical issues like putting on a patch, using a breathing mask, strapping someone in a car seat or dressing. Giving enemas is more intimate than that and is therefore bordering on abuse in the parents' view. Doubt causes body and mind to disagree:

I really felt that I didn't want to, no I didn't want to do this. Although my brain said "yes, I had to do this", my body said "no, no, no..." (Mother of a boy, 12 years old)

There and then medication might be administered despite resistance. Their parental responsibility to give treatment as prescribed is fulfilled, but with feelings of remorse and fears that bad memories will be imprinted on the children forever. On the other hand, sometimes despite the worst imaginable expectations, the rectal enema procedure went smoothly. There were times when the child asked for an enema to be able to empty its bowel more effectively, having

previously experienced the benefit of the treatment. Sometimes the procedure is a success, with no complaints from the child, despite the parents' second thoughts.

2.11 | Affirmation or not to give treatment

Affirmation is one reason for parents to give the treatment. There is often a history of struggling with the child's constipation and no one wants to go back to the initial condition. This motivates parents to move forward, determined to help no matter what:

I think that she really needs this enema, otherwise she will go back to the state she was in before we gave her the first enema, when she had a terrible stomachache. And that made me decide to give it. Let's do it, yes. (Mother of a girl, 3 years old).

Affirmation from healthcare personnel is an important source of power and assurance of what to do. When they feel enlightened, well informed and supported in the struggle, parents can adopt a calmer frame of mind with increased confidence. Praise is appreciated after doing well and encourages them to continue. Some parents reasoned that the treatment is a parental responsibility, a task to be done if results are to be expected, feeling the healthcare system expects them to handle the treatment. Information and knowledge offered by healthcare personnel can have a calming effect and strengthen the parents resolve to treat. Feelings are still conflicted, but not as strongly:

If I hadn't been given enough information and had been a bit ignorant about the medication, I think the feelings of being abusive would have been much worse for me. (Mother of a girl, 2 years old).

Sometimes, comparison with others and the desire to be competent along with praise and affirmation empowered parents to continue even when it felt wrong. Uncertainty about the situation combined with affirmation may explain why they sometimes act against their own beliefs, which in hindsight might be a negative experience. Parents turn to healthcare personnel for clearance to do things that feel wrong, leaning on authority to justify their actions.

One parent can act as a reassuring sounding board for the other and share the decision-making. As one parent is usually calmer than the other, they can support each other. Parents considered it easier to give enemas together, both practically and emotionally. Frustration directed towards the other parent is often just an expression of helplessness about the situation. It is important to share the experience with someone close to feel that it is right to continue.

The experience of giving constipation treatment at home can even build a stronger relationship with the child and develop more

profound trust. When children affirm that treatment is all right, parents feel less distressed. Generally, the main reason for continuing the treatment is that the positive effect on the child is evident:

Even if this [the treatment] is such a difficult situation, it helps and makes you feel... It is hard beforehand but afterwards when you see how well he feels, it makes you feel good to. (Mother of a boy, 2 years old).

When results are evident, parents feel relief and happiness for themselves and for the child. This makes the struggle worthwhile and affirms them in their decision to treat.

3 | DISCUSSION

In this study, we found that constipation treatment causes parents to question their parental identity and what it means to be a good parent. When they force treatment on children, they feel abusive and that they are acting against their will as parents. There is a conflict between doubt and second thoughts about the treatment, the urge to treat based on the child's needs and affirmation from healthcare professionals. That giving constipation treatment stirs up feelings of frustration or abuse is also found in other studies (Kaugars et al., 2010; Nisell, Ojmyr-Joelsson, Frenckner, Rydelius, & Christensson, 2003; Vejzovic, Bramhagen, Idvall, & Wennick, 2015). The present study confirms that parental values collide with conflicting emotions when they follow physicians' prescriptions. Acting in the best interest of the child but against the child's and sometimes their own will and beliefs violates their own desire to be a good parent. This is the essence of the situation, that is, discordant beliefs that shake their core identity as parents.

Hill et al. (2019) states that there is no single right way to be a good parent to a child with an illness and every parent identifies their own beliefs and can redefine them over time. This corresponds to the essence of the present study, where personal cornerstones in parenting are revalued. Contemporary society and child-rearing styles are influential and have an impact on parents' choices of conduct. Being a parent comes with responsibilities. This entails making a grown-up decision to follow prescriptions and support the child through the process, which is not necessarily easy. Societal influences must be critically evaluated by every parent when deciding what is means for them to be a parent. October, Fisher, Feudtner, and Hinds (2014) found that a good parent should focus on the child's quality of life, advocate for their child with the medical team and put their child's need above their own. It can be challenging to understand what the child's needs are, to focus on them and disregard one's own experience. Parenting sometimes involves levels of firmness when children, because of age or developmental stage, do not understand their best interest in the long term. Understanding the benefits of eradicating constipation symptoms by receiving treatment is a typical situation where children might not understand why the parent is inflicting discomfort here and now.

Children and what are best for them are the primary focus and responsibility of paediatric healthcare professionals when providing evidence-based information about treatment. Unfortunately, treatment guidelines rarely consider the complexity of everyday life or experiences and emotions related to the treatment. Healthcare professionals need to understand and communicate the challenges parents face with the conflicting emotions that arise when making treatment decisions for their child. The most important task is to give all the necessary information and knowledge. Therefore, to help parents prepare and to offer support, it is necessary to discuss with them the difficulties related to the administration of medication, as proposed by Koppen et al. (2018). Medical treatment decisions are made by professionals, but ultimately it falls on the parents to decide whether to treat. To make that informed decision they need to understand the consequences of both choices; if they treat, they might have to go through the hardship of forcing the child to cooperate, deal with the possible feelings of abuse and follow through despite opposition. If they decide not to treat, the chronic constipation might persist for a much longer period, with all its related symptoms and psychosocial consequences. Functional constipation seldom resolves spontaneously. According to Levy, Lemmens, Vandenplas, and Devreker (2017) every professional caregiver must have the knowledge and time to explain, coach and motivate parents and their children through every treatment plan. Modin et al. (2016) stresses the importance of support for the choices and management behaviours of parents to facilitate treatment success. If this is achieved, we believe that the risk of pushing parents to act in ways they will regret or feel guilty about will decrease. The findings in the present study strengthen the belief that healthcare professionals need knowledge and time to give support in treatment situations as this reaffirms parents.

The findings show a perceived difference between the experiences of forced situations such as dressing or strapping a child in a car seat and the forced constipation treatment situation. One thing that could possibly make this situation special is that the children do not have any underlying disease, just the idiopathic or functional symptoms that are 'only' a clinical diagnosis. This might make it more difficult for the parents to justify the act of treatment than if there were a sickness or a diagnosis of an actual disease in the background such as asthma, diabetes, rectal malformation or cancer that required some form of forced treatment. What is interesting is that the experiences of being abusive and not respecting the child's autonomy existed regardless of the child's age. There was no difference in perceived abusiveness between physically restraining a toddler or having to persuade an adolescent. This suggests that parents questioning their ability to follow their good-parent beliefs is not affected by the child's age or duration of symptoms but simply by the dichotomy of what is best for the child.

Another aspect is views on sexuality. The experience was described as aggravated because it involved the child's private parts. Force and disrespect for the child's will was one thing, but the intimate aspect took the situation to another level. Moreover, adult views on nudity and the lower abdomen are not necessarily the same as those of the children. Toddlers are seldom concerned about being naked or changing their nappy. According to Volbert (2000), children predominantly describe

the purpose of genitalia as elimination. Objections about receiving an enema may have nothing to do with being naked, but rather about the fear of the subsequent stomach ache arising from bowel movements or from being held and restrained. de Graaf and Rademakers (2006) state that the influence of the adult view on sexuality must be taken into consideration when exploring the experiences of rectal medication. In that sense every parent and professional caregiver could benefit from reaching into themselves to search for possible explanations as to why rectal treatment might evoke such strong feelings. A Danish study notes a cultural shift in the society on children's sexuality and nudity, suggesting that it is the adults' thoughts that give nudity a sexual aspect (Leander, Larsen, & Munk, 2018). This might be the case in Sweden as well, where views and values are somewhat similar to those in Denmark.

The identity crisis, with doubt and ambivalence about how to handle the constipation situation, is experienced as shameful and lonely, which may have its origins in the very private nature of the situation. As this phenomenon has a considerable impact on parents and on relationships and everyday family life, it needs to be further explored in future studies.

3.1 | Limitations

There is a risk that the families invited to participate in this study had already expressed difficulties or concerns about the treatment. Hence, they might represent the severe end of the problem, which makes it difficult to know whether these findings can be generalized to all parents of children with functional constipation. These families might also be more prone to participate to receive help and support. Thus, parents of children for whom treatment is a minor issue might never have been invited to participate.

The essential meaning structure of this study is based on biological parents' experiences but can be generalized to any caregiver such as grandparents or adoptive parents, perhaps even to professional caregivers. It might also be possible to apply the essential meaning structures to other medical treatment situations where the child refuses treatment or where the caregiver is hesitant and experiences difficulties in carrying out prescribed treatment. However, as this study focused specifically on the phenomenon of pharmacological constipation treatment given in the child's home, its transferability to other medical situations where parents hesitate to treat, while possible, is not certain.

Views on rectal treatment can vary with different cultural and social situations. The essential meaning structure of the present study reflects the cultural perspective in a Swedish context and is therefore valid only in similar contexts.

4 | CONCLUSIONS

The findings illustrate the importance of supporting the treatment decision of parents and enabling them to come to informed decisions

about how to act. One important finding is that constipation treatment in children, a minor medical issue in one sense, puts families in crisis. Constipated children need to be treated with more focus and prompt management to prevent these families from lingering in the healthcare system longer than necessary.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

GF, EM, PR: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; GF, EM, KD, PR: Involved in drafting the manuscript or revising it critically for important intellectual content; GF, EM, KD, PR: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; GF, EM, KD, PR: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.14539>.

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REFERENCES

- Bardisa-Ezcurra, L., Ullman, R., & Gordon, J. (2010). Diagnosis and management of idiopathic childhood constipation: Summary of NICE guidance. *BMJ: British Medical Journal (Overseas & Retired Doctors Edition)*, 340(7758), c2585. <https://doi.org/10.1136/bmj.c2585>
- Bekkali, N. L., van den Berg, M. M., Dijkgraaf, M. G., van Wijk, M. P., Bongers, M. E., Liem, O., & Benninga, M. A. (2009). Rectal fecal impaction treatment in childhood constipation: Enemas versus high doses oral PEG. *Pediatrics*, 124(6), e1108–e1115. <https://doi.org/10.1542/peds.2009-0022>
- Bongers, M. E., & Benninga, M. A. (2011). Long-term follow-up and course of life in children with constipation. *Journal of Pediatric Gastroenterology and Nutrition*, 53(Suppl 2), S55–S56.
- Bongers, M. E., van Wijk, M. P., Reitsma, J. B., & Benninga, M. A. (2010). Long-term prognosis for childhood constipation: Clinical outcomes in adulthood. *Pediatrics*, 126(1), e156–e162. <https://doi.org/10.1542/peds.2009-1009>
- Dahlberg, H., & Dahlberg, K. (2020). Phenomenology of Science and the Art of Radical Questioning. *Qualitative Inquiry*, 26(7), 889–896. <https://doi.org/10.1177/1077800419897702>
- Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2. ed.): Studentlitteratur.
- de Graaf, H., & Rademakers, J. (2006). Sexual Development of Prepubertal Children. *Journal of Psychology & Human Sexuality*, 18(1), 1–21. https://doi.org/10.1300/J056v18n01_01
- Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J., ... Hinds, P. S. (2015). Good-Parent Beliefs of Parents of Seriously Ill Children. *JAMA Pediatrics*, 169(1), 39–47. <https://doi.org/10.1001/jamapediatrics.2014.2341>
- Hill, D. L., Faerber, J. A., Li, Y., Miller, V. A., Carroll, K. W., Morrison, W., ... Feudtner, C. (2019). Changes Over Time in Good-Parent Beliefs Among Parents of Children With Serious Illness: A Two-Year Cohort Study. *Journal of Pain & Symptom Management*, 58(2), 190–197. <https://doi.org/10.1016/j.jpainsymman.2019.04.018>
- Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., ... Furman, W. L. (2009). "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care and resuscitation decisions for their children. *Journal of Clinical Oncology*, 27(35), 5979–5985. <https://doi.org/10.1200/jco.2008.20.0204>
- Hyams, J. S., Di Lorenzo, C., Saps, M., Shulman, R. J., Staiano, A., & van Tilburg, M. (2016). Functional Disorders: Children and Adolescents. *Gastroenterology*, <https://doi.org/10.1053/j.gastro.2016.02.015>
- Kaugars, A. S., Silverman, A., Kinservik, M., Heinze, S., Reinemann, L., Sander, M., ... Sood, M. (2010). Families' perspectives on the effect of constipation and fecal incontinence on quality of life. *Journal of Pediatric Gastroenterology and Nutrition*, 51(6), 747–752. <https://doi.org/10.1097/MPG.0b013e3181de0651>
- Koppen, I. J. N., van Wassenae, E. A., Barendsen, R. W., Brand, P. L., & Benninga, M. A. (2018). Adherence to Polyethylene Glycol Treatment in Children with Functional Constipation Is Associated with Parental Illness Perceptions, Satisfaction with Treatment and Perceived Treatment Convenience. *Journal of Pediatrics*, 199, 132–139.e131. <https://doi.org/10.1016/j.jpeds.2018.03.066>
- Koppen, I., von Gontard, A., Chase, J., Cooper, C. S., Rittig, C. S., Bauer, S. B., ... Benninga, M. A. (2016). Management of functional nonretentive fecal incontinence in children: Recommendations from the International Children's Continence Society. *Journal of Pediatric Urology*, 12(1), 56–64. <https://doi.org/10.1016/j.jpurol.2015.09.008>
- Koppen, I. J. N., Vriesman, M. H., Saps, M., Rajindrajith, S., Shi, X., van Etten-Jamaludin, F. S., ... Tabbers, M. M. (2018). Prevalence of Functional Defecation Disorders in Children: A Systematic Review and Meta-Analysis. *Journal of Pediatrics*, 198, 121–130.e126. <https://doi.org/10.1016/j.jpeds.2018.02.029>
- Leander, E. B., Larsen, P. L., & Munk, K. P. (2018). Children's Doctor Games and Nudity at Danish Childcare Institutions. *Archives of Sexual Behavior*, 47(4), 863–875. <https://doi.org/10.1007/s10508-017-1144-9>
- Levy, E. I., Lemmens, R., Vandenplas, Y., & Devreker, T. (2017). Functional constipation in children: Challenges and solutions. *Pediatric Health, Medicine and Therapeutics*, 8, 19–27. <https://doi.org/10.2147/phmt.S110940>
- Lindgren, H., Nejstgaard, M. C., Salö, M., & Stenström, P. (2018). Evaluation of bowel function in healthy children: Untreated constipation is common. *Acta Paediatrica*, 107(5), 875–885. <https://doi.org/10.1111/apa.14225>
- Lisboa, V. C., Felizola, M. C., Martins, L. A., Tahan, S., Neto, U. F., & de Moraes, M. B. (2008). Aggressiveness and hostility in the family environment and chronic constipation in children. *Digestive Diseases and Sciences*, 53(9), 2458–2463. <https://doi.org/10.1007/s10620-008-0230-1>
- Maurer, S. H., Hinds, P. S., Spunt, S. L., Furman, W. L., Kane, J. R., Baker, J. N., ... Baker, J. N. (2010). Decision making by parents of children with

- incurable cancer who opt for enrollment on a phase I trial compared with choosing a do not resuscitate/terminal care option. *Journal of Clinical Oncology*, 28(20), 3292–3298. <https://doi.org/10.1200/JCO.2009.26.6502>
- Modin, L., Walsted, A. M., Rittig, C. S., Hansen, A. V., & Jakobsen, M. S. (2016). Follow-up in Childhood Functional Constipation: A Randomized, Controlled Clinical Trial. *Journal of Pediatric Gastroenterology and Nutrition*, 62(4), 594–599. <https://doi.org/10.1097/mpg.0000000000000974>
- Mugie, S. M., Di Lorenzo, C., & Benninga, M. A. (2011). Constipation in childhood. *Nature Reviews Gastroenterology & Hepatology*, 8(9), 502–511. <https://doi.org/10.1038/nrgastro.2011.130>
- Nisell, M., Ojmyr-Joelsson, M., Frenckner, B., Rydelius, P. A., & Christensson, K. (2003). How a family is affected when a child is born with anorectal malformation. Interviews with three patients and their parents. *Journal of Pediatric Nursing*, 18(6), 423–432.
- October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The parent perspective: "being a good parent" when making critical decisions in the PICU. *Pediatric Critical Care Medicine*, 15(4), 291–298. <https://doi.org/10.1097/PCC.0000000000000076>
- Pellatt, G. C. (2007). Clinical skills: Bowel elimination and management of complications. *British Journal of Nursing*, 16(6), 351–355. <https://doi.org/10.12968/bjon.2007.16.6.23008>
- Tabbers, M. M., Boluyt, N., Berger, M. Y., & Benninga, M. A. (2011). Clinical practice : Diagnosis and treatment of functional constipation. *European Journal of Pediatrics*, 170(8), 955–963. <https://doi.org/10.1007/s00431-011-1515-5>
- Tabbers, M. M., DiLorenzo, C., Berger, M. Y., Faure, C., Langendam, M. W., Nurko, S., ... Benninga, M. A. (2014). Evaluation and treatment of functional constipation in infants and children: Evidence-based recommendations from ESPGHAN and NASPGHAN. *Journal of Pediatric Gastroenterology and Nutrition*, 58(2), 258–274. <https://doi.org/10.1097/mpg.0000000000000266>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- van Ginkel, R., Reitsma, J. B., Buller, H. A., van Wijk, M. P., Taminiau, J. A., & Benninga, M. A. (2003). Childhood constipation: Longitudinal follow-up beyond puberty. *Gastroenterology*, 125(2), 357–363. [https://doi.org/10.1016/s0016-5085\(03\)00888-6](https://doi.org/10.1016/s0016-5085(03)00888-6)
- Van Wijngaarden, E., Van Der Meide, H., & Dahlberg, K. (2017). Researching Health Care as a Meaningful Practice: Toward a Nondualistic View on Evidence for Qualitative Research. *Qualitative Health Research*, 27(11), 1738–1747. <https://doi.org/10.1177/1049732317711113>
- Vejzovic, V., Bramhagen, A. C., Idvall, E., & Wennick, A. (2015). Parents' experiences when their child is undergoing an elective colonoscopy. *Journal for Specialists in Pediatric Nursing*, 20(2), 123–130. <https://doi.org/10.1111/jspn.12109>
- Volbert, R. (2000). Sexual Knowledge of Preschool Children. *Journal of Psychology & Human Sexuality*, 12(1–2), 5–26. https://doi.org/10.1300/J056v12n01_02
- Vriesman, M. H., Rajindrajith, S., Koppen, I. J. N., van Etten- Jamaludin, F. S., van Dijk, M., Devanarayana, N. M., ... Benninga, M. A. (2019). Quality of Life in Children with Functional Constipation: A Systematic Review and Meta-Analysis. *Journal of Pediatrics*, <https://doi.org/10.1016/j.jpeds.2019.06.059>
- World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. (2013). *JAMA*, 310(20), 2191–2194. <https://doi.org/10.1001/jama.2013.281053>
- Yoo, T., & Bae, S. H. (2017). Efficacy and Safety of Combined Oral and Enema Therapy Using Polyethylene Glycol 3350-Electrolyte for Disimpaction in Pediatric Constipation. *Pediatric Gastroenterology, Hepatology & Nutrition*, 20(4), 244–251. <https://doi.org/10.5223/pghn.2017.20.4.244>
- Youssef, N. N., Langseder, A. L., Verga, B. J., Mones, R. L., & Rosh, J. R. (2005). Chronic childhood constipation is associated with impaired quality of life: A case-controlled study. *Journal of Pediatric Gastroenterology and Nutrition*, 41(1), 56–60. <https://doi.org/10.1097/01.mpg.0000167500.34236.6a>
- Zeevenhooven, J., Koppen, I. J., & Benninga, M. A. (2017). The New Rome IV Criteria for Functional Gastrointestinal Disorders in Infants and Toddlers. *Pediatric Gastroenterology, Hepatology & Nutrition*, 20(1), 1–13. <https://doi.org/10.5223/pghn.2017.20.1.1>

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