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INTRODUCTION

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is a chronic illness. The overall incidence among children is increasing in Scandinavia (Perminov et al., 2009; Malmborg, Grahnquist, Lindholm, Montgomery & Hildebrand, 2013; Lehtinen, Pasanen, Kolho, & Auvinen, 2015) as well as in the United States (Malaty, Fan, Opekun, Thibodeaux & Ferry, 2010), approximately 25 percent of all individuals diagnosed with IBD are adolescents (Kappelman et al., 2007). IBD is an illness that entails periods of uncontrolled disease activity with intestinal inflammation, and periods of remission (Benchimol et al., 2014). Periods of disease activity are characterised by abdominal pain, diarrhoea, rectal bleeding, weight loss, pubertal delay, fever, fatigue, and arthritis (Dubinsky 2008). Thus, for a child diagnosed with IBD, treatment **requires** regular contact with **a** health care due **provider to obtain** the required medication, which necessitates regular blood tests and follow-ups of the illness, including colonoscopy in order to examine the intestines (Hommel, Davis & Baldassan 2008; Oestrup Olsen, Jensen, Larsen & Sorensen 2015). The goal of treatment is to eliminate symptoms, normalise quality of life, restore growth, and prevent complications, while minimising any adverse effects of the medication (Rosen, Dhawan, & Saeed 2015). Previous research about IBD in children has primarily been quantitative and focused on the children's health-related quality of life (e.g. Hommel et al., 2008; Gray, Denson, Baldassano & Hommel 2011; Lindfred, Saalman, Nilsson, Sparud-Lundin, & Leep 2012; Mueller et al., 2016). This research has demonstrated that children with IBD have higher rates of stress and are at higher risk of developing depression in comparison with their healthy peers (Greenley, Hommel, Nebel, Tara Rabaion & Shun-Hwa 2010; Reigada et al., 2011). Research has also shown that the risk of developing depression is similar to that in children with other chronic illnesses, such as diabetes (Mackner & Crandall 2006). In a study by **Yi et al., (2008)**, adolescents reported lower general health perceptions

and greater overall life stress than the healthy controls. Furthermore, a **meta-analysis** of the psychosocial adjustment of youths with IBD showed that the quality of life was perceived to be lower by both children and their parents compared to healthy controls (Greenley et al., 2010). Studies have also highlighted the fact that 20 **percent** of the children with IBD miss significantly more school days (more than 3 weeks of school) than their healthy peers (among whom only 4 **percent** miss as many days). Thus, children with IBD may experience more difficulties in school than their healthy peers (Mackner, Bickmeier & Crandall 2012). Further, it has been demonstrated, by means of both questionnaires and interviews, that the symptoms of the illness can be socially embarrassing and humiliating (Engström 1999). When the disease is active, the child may spend a great deal of **time on** the toilet, which may, in turn, limit his/her social activities (Nicholas et al., 2007; Dubinsky 2008). **Considering** children are often diagnosed at school age, it is reasonable to think that requiring the toilet frequently during school hours can be a great burden, especially **because** healthy schoolchildren have been found not to use school toilets during school hours as often as they would like. This because of different barrier, for example, inadequate locks (Norling, Stenzelius, Ekman & Wennick, 2015). **Children** with symptoms of IBD do not speak openly about their toilet needs or about symptoms related to the illness; instead, they tend to keep their thoughts to themselves (Nicholas et al., 2007; Vejzovic, Wennick, Idvall, & Bramhagen 2014; Oestrup Olsen et al., 2015). Young adults with **IBD**, aged between 18 and 29 **show**, a similar tendency; they also experience a higher degree of stigma in comparison with young adults with type 1 diabetes because of the taboo nature of their illness symptoms (Sanders 2014). Another study, including 77 children aged 11-16, and using mixed methods, found that **even if the child** overall expressed well-being and a relatively good ability to handle her/his IBD, **her /his well-being and her/his** ability to handle the illness, were impaired by the symptoms of IBD, as well as by a disease-related poor physical condition and negative sleeping patterns

(Lindfred et al., 2012). Apart from studies showing that there are many issues (e.g., social isolation, anxiety, dependent behaviour) related to IBD that affect the quality of life in children (e.g., Lindfred et al., 2012; Mueller et al., 2015), there is a conspicuous absence of research-based knowledge focused on the children's feelings and thoughts when they live with IBD (Nicholas et al., 2007; Oestrup Olsen et al., 2015). Knowledge about the **child's** own experience could provide a better understanding of **his/her** needs when having IBD, which could increase opportunities to improve the quality of paediatric care. Therefore, the aim of the present study was to illuminate the meaning of children's lived experiences of IBD.

METHODS

A phenomenological hermeneutical design was used **to illuminate** the meaning of the children's lived experiences.

Participants

Data was obtained from seven children (three girls and four boys) aged 13-18, who were diagnosed with UC. The inclusion criteria were: children, age 10-18 years, a diagnosis of IBD after undergoing a colonoscopy in a randomised controlled trial (RCT) ($n = 26$) conducted by Vejzovic, Wennick, Idvall, Agardh, & Bramhagen (2016). In total, 22 children, who fulfilled the inclusion criteria, were asked to participate, 15 of whom declined. The children were recruited at the Department for Pediatric Gastroenterology at a University Hospital in Sweden.

Procedure and data collection

Information about the study was sent as a letter to both the children and their parents. They also received an addressed reply-envelope and a form to fill in if they did not want to participate. Those who wanted to participate were contacted by the first author by telephone.

After they had been given time to reflect, the child as well as their parents were asked whether the child wished to participate.

Interviews

All interviews were conducted in 2015, between July and October, by the first author, who was not involved in the child's care. The child chose the place for the interview and it was conducted in the family's home ($n = 1$), in a secluded parlour at the hospital ($n = 5$), or in a meeting room at the child's school ($n = 1$). Parents ($n = 5$) who accompanied their child waited for him/her in another room; thus, no parents were present during the interviews. The duration of the interviews varied from 44 to 70 minutes. All interviews started with an opening question allowing the children to talk about "their life before the diagnosis", followed by an open question about "life with IBD". Follow-up questions, such as "What do you mean?", "Could you explain?", "Could you tell me a bit more about that?", "How did you feel when ... ?", and "What did you think about ... ?", were asked throughout the interviews in order to clarify the child's narrative and check the first author's own understanding of the narrative. Having to talk about the illness during the interviews may awake memories, which is why an opportunity for debriefing with a psychologist was prepared if the child needed this. However, no participant chose to utilise this opportunity.

Data analysis

Data was analysed using a phenomenological hermeneutical method influenced by Lindseth and Norberg (2004). This method is based on Paul Ricoeur's interpretation theory from 1976 and follows the hermeneutical circle when interpreting the text. This means that the text was understood by moving from the understanding of the whole text to the understanding of its parts and then back again to the whole text, as well as by the movement between understanding and explanation. The open-minded approach, which means being open enough to allow the text to speak to oneself, is recommended (Lindseth & Norberg 2004). In order to

keep an open-minded approach, the authors discussed their own pre-understanding throughout the analysis process. Three of the authors are paediatric nurses. The first author's experience in paediatrics as well as interview techniques made it possible to reflect on the child's answers during the interview and to ask relevant follow-up questions. The follow-up questions led to a richer description. The first author was also interviewed about her own pre-understanding by a colleague who was not involved in this study. This was done in order to increase the awareness of her pre-understanding and to reflect on it. An independent researcher who is an expert in theories of health and disease was also involved in the discussions of the interpretation of the text. The analysis of the children's experiences started with the interviews being transcribed and then continued through three phases: naive understanding, structural analysis, and comprehensive understanding. Organising the text into meaning units was the next stage of the process (structural analysis). The text was read thoroughly in order to identify narratives about the lived experience of UC. This was then transformed into sentences, which were as close to the initial text as possible. The structural analysis was a process during which impressions of the naive reading were rejected or confirmed. During the last part of the process (comprehensive understanding), the findings of the study were linked to existing literature, as well as to Ingmar Pörn's theory of adaptedness (1993), in order to gain a deeper understanding of the meaning of the children's lived experience of having IBD. Added to that, it allowed for an explanatory framework for the children's problems, and their handling of them.

Ethical considerations

The children and their parents were informed that participation was voluntary and that the child could withdraw her/his participation at any time without any consequences. Written informed consent was obtained from both parents and children above the age of 15. In families with children younger than 15 years of age, the parents gave their written informed

consent, while the child gave verbal assent. **Because** previous research has shown that children diagnosed with IBD have a need to talk but usually do not talk openly about their abdominal symptoms, they might find it beneficial to share their lived experience with someone who will listen but who is not involved in their care. This opportunity may not otherwise be offered to them. Ethical approval **was** granted by the Regional Ethical Review Board in Lund (Ref. No. 2015/ 340).

FINDINGS

At the time of the interview, all of the children had been living with their diagnosis for more than one year.

Naive understanding

The first prediction of the meaning of the children's lived experience can be presented as a constant search for opportunities to attain a normal everyday life, regardless of the negative impact of IBD, both physically and emotionally. The children strove to perceive themselves as healthy, and they needed to be perceived as healthy, especially when experiencing symptoms of IBD. During symptom-free times the children felt good and healthy, but the fear that the symptoms might be getting back at any time was always present. The children expressed that life with the symptoms of the illness was difficult, **because** the symptoms were uncontrolled, **and because of** different limitations in their everyday life **during symptom periods.**

Structural analysis

The meaning of the children's lived experience of IBD can be summed up in one theme: *A daily struggle to adapt and to be perceived as normal*. The main theme consists of four sub-themes: *being healthy despite the symptoms, being healthy despite being afraid, being healthy despite a sense of being different, and being healthy despite needing support*. These sub-themes are presented below with quotations from the participants to support the confirmability of the findings.

Being healthy despite the symptoms

The children viewed themselves as healthy or normal, and they began their narrations by expressing that they felt good. In order to convince themselves that they were healthy, they linked their IBD exclusively to the intestine and only to the time that they had symptoms from IBD. *"I feel healthy when I don't have any onsets ... really good ... just need to take my medicine"* (IP6). When they felt healthy, they did not think about the disease and they experienced that everything was "normal", which is how they referred to the time when the **symptoms was not present**. *"I don't think a lot about it ... I've accepted that things won't return to normal, even if there are moments when it feels as if it's"* (IP3). The feeling of being healthy changed over time as the children had relapses. They explained that the physical symptoms experienced throughout the duration of the illness were disruptive to their everyday life. Thus, they described how they felt victim to stomach pain as well as bloating and often had to visit the toilet; one child described this state by saying that *"the head can only focus on the stomach"* (IP1). They further disclosed their inability to concentrate, as well as mentioning a decrease in energy levels and an overwhelming need to rest. During such periods of symptoms, especially while in school, they did their best to be perceived as healthy and they refrained from visiting the toilet, which led to further pain and discomfort. They mentioned that the symptoms prevented them from leading "normal" lives, reducing the extent of

opportunities granted to them every day. The periods in which pain was experienced were extensive and strenuous. One child stated: *“If I have a stomach ache ... then it’s like I have a cold, but actually it’s my stomach that’s hurting ... but a cold doesn’t last for one year ... it’s tough ...”* (IP5).

If a relapse occurs, often the children will stay home from school instead of showing themselves as weak. Although the opportunity to stay home may somewhat lessen the physical discomfort, the stress over missing out on lessons and activities can induce additional discomfort, leading to further absence from school. Upon experiencing symptoms of UC, along with the side-effects of the medication, the children chose to keep their distance from their peers because of their need to be perceived as healthy.

Being healthy despite being afraid

The children described feeling healthy but said that they were afraid of being unable to control the need to pass gas, or “triggers”, especially during school time. The constant fear that something unpleasant might occur limited them in their daily life. *“There have been some incidents ... where I went to the toilet in my trousers but ... yes... it’s very difficult not being able to control ... [a pause] ... you don’t have complete control over it ...”* (IP3). They described how, regardless of feeling healthy, they often had to decline invitations to join their friends for participation in various activities because of unpleasant feelings linked to uncontrolled IBD. This led to thoughts of exclusion; they were afraid that after an extended period of time, their friends would no longer ask them to be part of the group. *“I was scared of being excluded as I couldn’t do the same things as my friends ...”* (IP2). During periods when the children felt healthy, they also felt confused **because symptoms** could come and go unexpectedly. This resulted in a constant dread of potential mishaps. *“... something which added to the confusion was that the pain came and went ... it was gone for a few days and*

then came again ... when it disappeared I thought it felt great, but then it came back, which made me wonder” (IP2).

The children declared that they wished to be perceived as healthy, and they were, consequently, afraid to speak about their illness. They said that they felt free to converse with their parents on the subject, but that they rarely went into detail about their thoughts or feelings **because** they did not wish to worry their parents. Changes that might occur within the body if the intestine needed to be removed provoked fear, and the children said that they did not share their feelings about this with anyone. They found it embarrassing to discuss digestive issues with their comrades, especially regarding their persistent toilet needs. The children expressed that they perceived themselves as healthy, but that they were afraid to be perceived as different from their friends.

Another aspect of these children’s lives that caused them to be afraid was that the other children in their class could not relate to their situation and therefore could not understand what they were going through. They confessed that they would rather experience their discomfort in solitude than be perceived as not healthy, or different, by their peers. *“I think that I would have made them uncomfortable ... a prejudice of sorts that they have against me is when they say ... come on, it’s just your stomach ... they can’t understand, they go to the toilet like once every other day ... ahh ... I can’t keep it inside me ... I just need to put up with it, so ... it’s actually hard [tears start coming]” (IP6).*

Every child mentioned the sympathy they received from their teachers and school nurses, and these persons’ willingness to help them facilitate their school work. However, the children did not seek their help often because they were afraid to reveal their real problems. Instead, they did their best to manage their tasks independently, which gave them a sense of being normal and similar to their peers. When they described “the normal state”, they referred to the periods

when the symptoms were minimal and they felt healthy. At such times, they perceived themselves like everyone else and they did not think about the disease too much.

Being healthy despite a sense of being different

The children indicated having close friends to whom they could “talk about everything”. A strong desire to make friends that understood them and that did not perceive them as being different, emanated from the children’s narrations. However, it appeared that they spoke mainly about the illness in general with their friends and did not disclose more specific information regarding symptoms or thoughts/feelings experienced throughout the illness period. The reasons for this varied from child to child; one of them, for example, did not wish to go into detail and potentially alarm a classmate or friend. *“I’m happy that they don’t have it and I feel like I don’t want to talk about it ... they don’t need to know that I think of poo all the time, know how hard things are for me ... diarrhoea ten times a day and then also ... what can I do about it ... I wish I was more comfortable with it ... say”* (IP7).

The children expressed their belief that other children simply did not understand what they were going through. They explained their preference for making contact with a fellow classmate who suffered from similar symptoms because there is a mutual understanding between those who are afflicted with IBD. They felt the need to share thoughts and experiences with peers who partake in the same struggle. *“... I thought that I was the only one ... that I was really the only one ... I haven’t heard about others, and then ... then he comes and tells me and I’m like, what?... that was good ... well, it’s not good that he has it, but it’s good for me that he said it ... we have, like, found each other who have a similar disease ...”* (IP1). As a rule, the children did not know of others within their general surroundings who suffered from similar symptoms; their fellow students were perceived to live fairly uncomplicated lives. Overall, the children in this study tended to seek acknowledgement from

their peers, and a simple question such as “how are you?” could make them feel validated and encouraged. They expressed that the opportunity to share their perceptions of their lived experiences was important. Some claimed, during the interview, that it was the first time they felt that they could **verbalize** their feelings. “... *if I’d had someone close to me I would perhaps have felt freer, too ... yes ... I think I’ll have a different view of myself after this interview ... I haven’t verbalised this ... so, on the whole ... I just write my alternatives in my head, sort of ... and then I try not to think about it ... what to do, like ... now I realise that I didn’t improve this way ... I realise that I’ll have to try to improve a bit more ...*” (IP6).

Being healthy despite needing support

The children also expressed that their parents played an important role in their everyday lives. The parents were generally recognised as being well-informed, demonstrating an interest in their child’s health and well-being as well as an understanding of their child’s struggles. The children agreed that their parents did indeed care about them. “*I stay at home ... mom also ... I don’t want to be alone when there’s bleeding ... it’s unpleasant ... yes ... being home alone when it’s like that ... now mom needs to make arrangements for being able to work from home ... I’m X ... she can’t just stay at home with me ... but she’ll do it*” (IP4).

The daily intake of medication acted as a constant reminder of the lingering illness, an illness they would possess for the rest of their lives. The children confessed to forgetting their medication occasionally, admitting that on some days it was avoided purposely, simply in order to dampen the impact the disease had on their everyday life. “*Nothing ... it doesn’t matter ... everyone forgets ... just so I don’t forget often ... they said that everyone forgets ... but mom, she wants me to always take it ... and ... yes ... I say that I am taking it ... and then I forget ... not a lot ... yes ...*” (IP4). It was the parents who assisted the children and reminded them to take their medication or food. For the children, their parents’ constant remarks

regarding abdominal pain and intake of food and medication, were just another indication of their chronic illness, which the children wished to disregard in order to endure their everyday life. They expressed that they were trying to cope with problems independently of their parents. This also gave them a sense of being no different from others. Furthermore, they said that they had been reluctant to talk about their illness **at** school, and they described how their parents had helped them to decide about informing their classmates.

Comprehensive understanding and reflections

In the last part of the analysis process, the findings of the study were pulled together in a theme, *a daily struggle to adapt and to be perceived as normal*, and linked to existing literature based on Pörn's theory of adaptedness (1993) in order to gain a deeper understanding of the meaning of the children's experience of UC. Pörn explains adaptedness as a balance (equilibrium) between the repertoire (ability) of the individual, including her health and competence, her goals (desire, wishes), and the environment. Adaptedness is an optimal or good state to be in, **because** being in balance allows the individual to achieve all her goals in the present (or expected) environment. This balance may be disturbed (creating a disequilibrium) in three ways. The ability might falter, the goals may become more ambitious and therefore harder to achieve, or the environment may become more challenging. There are also three ways in which the person can find a new balance, namely, by increasing her abilities (if possible), changing her goals, or changing the environment (Pörn 1993).

In this study, the presented interpretation is based on bringing together the naive understanding of the children's narrations, the result of the analysis, and the authors' pre-understanding of the phenomena. Our interpretation of the findings from the children's narratives is that the illness reduced their abilities to achieve their daily goals in the environment they were in. The children were not prepared to be diagnosed with a chronic

illness requiring lifelong treatment. They were not mentally prepared for all the limitations in daily life that the illness would entail, and they experienced that they were forced to accept the illness and the limitations caused by the illness.

The results show that this process was not easy. Thus, adapting to the new situation, which involves many limitations due to the unpredictable illness, was presented by the children as a daily struggle. The children in this age group (10-18 years) need to feel a sense of community with their peers, but they are restricted in their social functioning because of their pain, their concerns, and their feelings of being different. Our explanation is that the symptoms of the illness, such as pain, may influence the children's capacity to use different abilities, and **gives** rise to, for example, difficulties concentrating, which may, in turn, cause a disequilibrium in their daily life. The daily intake of medicine reduces the pain but may cause side effects, such as low energy or concentration problem. This can impact school work, which is an important part of the children's life. It is seen as important to live like one's peers, which means going to school, socialising with one's friends, and being able to perform different activities.

Our understanding is that UC may entail specific issues that are unique to this illness group.

As Nickolas et al. (2007) point out, worry related to IBD is more pronounced among adolescents than among younger children, which can also be connected to the natural development in this age group. The children with IBD may be socially isolated from their peers because of the nature of their illness, which can be **describe as** embarrassing and humiliating (Engström 1999). However, regardless of the difficulties caused by the illness, the content of every individual narrative was characterised by positive feelings. **The children in this study viewed themselves as healthy, linked their illness only to the intestine, wished to be perceive as healthy, and tried to find a new balance. In this way, they were able to manage daily life and maybe find new meaning or a new balance.**

According to our interpretation, the children in the present study show that they are aware of the problems connected to their illness. They describe different issues **that UC impact** in their everyday life, but also how they adapt to the new situation. This is in accordance with Van Der Zang-Loonen et al. (2004), who have shown that adolescents with UC use more avoidant coping styles than their healthy peers, which may be a result of the unique disease features, such as frequent stools and triggers. To be aware of the problems **allows on** understand the illness and have experience of it. However, this is often a protracted process, which is dependent on many factors, such as one's physical and emotional condition, the family situation, or the strength of the bond with one's friends. This process can result in a changed perception of health, and the children can find new meaning. The balancing of their desire to feel normal and have a normal daily life, with their concern for the progress of the illness, is only one of the challenges for the children.

Previous research has highlighted that most of the children with IBD report good health and well-being, and these studies describe strategies that the children use for handling relapses (Karwowski et al. 2009; Lindfred et al. 2012). **Describing** themselves as healthy, or being perceived as healthy by people in their environment, may help the children find a new equilibrium. In this study, the children expressed difficulties in opening up and talking about their illness or their toilet needs, which caused different limitations in their daily **life, and maybe** increased their feelings of being different. The children showed that they were capable of adapting to daily activities that they thought were important in order to feel healthy, but they also showed that they needed support. A common situation described by the children is connected **to school; they** felt that their school work was obstructed because the illness made them miss so many days. This is in accordance with results from other studies, which suggest that illness-specific factors may be linked to a lower rate of quality of life and school difficulties (Mackner et al. 2012).

The children showed the ability to adapt, but they also showed that they needed help from their parents and healthcare professionals, in order to understand, for example, the importance of being open and talking about their problems. They need the support of their parents, for example, in order to adhere to their treatment regimen, but they often resort to evasive coping in order to avoid disclosing their problems. In the present study, the children were undergoing puberty, which involves both physical and psychological changes. These changes, combined with an uncontrolled illness, can contribute to difficulties in the ability to adapt.

Previously, it has been recognised that the illness can have a negative impact on the children's quality of life and in some situations, for example, when the illness restricts their ability, the children may reformulate their goals with the help of healthcare professionals. Having knowledge about this could generate the opportunity to ensure that the children and their parents get adequate help.

The children in our study were struggling, but they felt that they could achieve their goals. Their goals were presented as a desire to manage their school work, to feel healthy in spite of having symptoms, and to keep the illness under control with the right food and medication. Thus, our interpretation is that when using Pörn's explication of the concept of adaptedness (1993), based on the holistic perspective that health is a balance between the repertoire, the environment, and the goals of the subject, a deeper understanding of the meaning of children's lived experience of IBD can be reached.

Study limitations

When data was collected, the intention was to interview children with IBD, including UC and CD, but only children having UC participated. This might be seen as a limitation of the present study because of reduced transferability to areas other than children with UC, due to the specific symptoms related to this disease. However, the aim of this study was to illuminate

the meaning of children's lived experience of UC as a part of IBD, and not to compare UC and CD. Furthermore, qualitative research is designed to shed light on the specific experience. In the present study, seven children were given the opportunity to narrate their experiences, due to the need of knowledge about the child's perspective of having IBD. However, the high study refusal rate may have biased the results. The recommended sample size for phenomenological studies ranges between 6-10 interviews (Denzin & Lincoln 1994; Kuzel 1999; and Morse 2000). Thus, although the sample was not large (n=7) the present study could be said to have a recommended number of participants. Further, the narrations were rich and the result can contribute to increased knowledge and increased opportunities for responsible healthcare professionals to help these children come into balance and achieve their goals.

Clinical implications

Children's lived experience of IBD, and the fact that children in this age group need to strive for adaptedness, and to experience themselves as healthy, can constitute an important basis for clinical implications. It is relevant **because** children often have ambitious goals that are **difficult to achieve**, due to the negative impact of IBD on their physical and emotional condition. In order for the children to manage daily life, they need support, which is something that healthcare professionals can offer, taking into account the variation of the children's needs. **When healthcare professionals understand the problems and have knowledge about the child's situation, the possibility to help the child with his/her adaptedness may increase.** Healthcare professionals could, for example, create opportunities for the children to meet other children with IBD, which could constitute an important factor in helping the children cope with their daily life.

Conclusion

The interpretation put forward in the study is that one meaning that can be extracted from children's experience of IBD is that they are struggling to adapt and be perceived as normal. This is a conscious process entailing a confrontation with various problems, such as ambitions and goals that are hard to achieve, due to reduced abilities resulting from the illness or from an inability to adapt to their environment.

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