

Bowel Cleansing Prior to Pediatric Colonoscopy: The Children's and Parent's Perspective

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Abstract: The paediatric care's primary priority is the best interest of children. For this to be possible necessitates both the children's and parent's perspective before planning different medical procedures which the child must undergo. The study's aim was to compare children's and parents' experiences of the child undergoing bowel cleansing prior to a colonoscopy. The interviews with children who have undergone a colonoscopy for the first time and parents who were present when their child underwent a colonoscopy were analysed using latent content analysis. Children (n=17) of both genders (12 girls and five boys) of an age ranging from 10-17 years and parents (n=12) were involved in this study. The findings were presented as one theme: The children's and parent's perspective of bowel cleansing. The results of the present study show both similarities and differences between children's and parents' experiences of a child's bowel cleansing prior to colonoscopy using polyethylene glycol with electrolytes as a laxative. The conclusion drawn from this study is necessity to use both child and parent's perspective to find strategies to help those children when bowel cleansing prior to colonoscopy.

Keywords: Children, Parents, Experience, Pediatric colonoscopy, Qualitative Approaches

1. INTRODUCTION

Paediatric care needs to be of good quality; it should meet the children's needs of safety and the best interest of the child should always be the primary priority in all actions concerning children. Children have a right to participate, receive information, and make health-related decisions [1]. However, historically, children have been excluded from the research process or decision making regarding their own health care [2, 3, 4]. One reason for this could be that research with children as participants raises many ethical questions [3,5]; another reason may be that children have been seen as vulnerable and are considered to lack the necessary competence due to their age and immaturity [4]. The best interest of the child has been considered from a *child's perspective*, which is based on the perceptions of parents and professionals of the child's desires and experiences [6]. According to earlier studies, children have positive experiences of being involved in discussions about their own care, which helps prepare them for what to expect and thus makes them feel less anxious [7,5]. Children also appreciate being given options

with regard to their care, and they feel valued when they are asked to make decisions [8,9]. In view of the recommendation that all treatment and procedures should be based on respect for the child's autonomy and integrity and that it should be performed with the child's active participation [1], today children are asked about their view on many aspects of their lives.

Claiming that paediatric care's primary priority is the best interest of children necessitates both the child and child's perspective before planning different medical procedures which the child must undergo [e.g. 2,5,10,11,12]. However, to the author's knowledge this necessitates more studies of both perspectives. The procedure prior to colonoscopy is only one example of an area which necessitates more knowledge. Children who need to undergo a colonoscopy often endure long periods of gastrointestinal (GI) symptoms [13]. Abdominal pain, diarrhoea, weight loss, GI bleeding, growth failure, and anaemia, are the most common symptoms in children. A safe, informative, and effective colonoscopy, performed in a child-friendly atmosphere with minimal distress to the child, is the recommended practice in the care of

children [14]. The role of colonoscopy is crucial for the diagnosis and monitoring of paediatric gastroenterology with as clean a bowel as possible for the appropriate detection of bowel disorders [e.g., 15, 16]. A variety of bowel cleansing regimens have been evaluated, but the most common in children are polyethylene glycol with electrolytes (PEG) [16, 17], which is also generally recommended by the ESPGHAN working group as a standard laxative, due to its cleansing efficacy and safety [18]. The recommended intake of PEG is 25-35 ml/kg bodyweight per hour until clear intestinal fluid is obtained, either orally or by nasogastric tube [19]. Previous quantitative studies show that the intake of large volumes of bad-tasting laxative was the most difficult part of the procedure prior to colonoscopy from both the child's and parents' perspective [10, 20, 21, 22, 23]. A limitation of research in this area is that children's and parents' experiences of bowel cleansing have been largely neglected [10, 11]. Thus, the aim of this study was to compare children's and parents' experiences of the child undergoing bowel cleansing prior to a colonoscopy.

2. METHOD

The study employed a qualitative design, using the interview for data collection and content analysis influenced by Graneheim and Lundman [24]. The interviews with children who have undergone a colonoscopy for the first time [10] and parents who were present when their child underwent bowel cleansing prior to a colonoscopy [11] were previously analysed [Burnard 25] but were reanalysed in the current study.

3. PARTICIPANTS AND PROCEDURE

The children and their parents from a hospital in southern Sweden were interviewed by the author regarding their experiences prior to colonoscopy. The selection of participants, both the children and parents, was performed in collaboration with the gastroenterological nurse in charge at the hospital who was not involved in the child's bowel cleansing but was responsible for the registration of the child. The children and parents were not interviewed together but they were interviewed on the same day, at most one week after the colonoscopy. PEG was the laxative used for bowel cleansing. The procedure before an elective colonoscopy entails a diet regimen at home before bowel cleansing, bowel cleansing with PEG as

inpatient, blood tests and anaesthesia prior to colonoscopy. The children orally received a weight-adjusted dosage of PEG 3350 with electrolytes: 25-35 ml/kg bodyweight per hour until clear intestinal fluid was obtained. The children and the parents were informed that participation was voluntary and that they could withdraw at any time without any consequences for their child. The interviews with children and parents were conducted during 2012 and 2013. A whole procedure was describe in previously studies [10, 11].

3.1. Children

Children (n=17) of both genders (12 girls and five boys) of an age ranging from 10-17 years were the participants of this study. Suspect inflammatory bowel disease (IBD), first time colonoscopy and that the child understood the Swedish language were inclusion criterion for the participation. Most of the interviews (n = 14) took place in the child's home; however, three were held in a private room at the hospital in accordance with the participant's wish. No parents were present during the interviews, however, the parents were present a few minutes at the beginning of their child's interview, and on one occasion, a cousin who provided emotional support was present during the interview [10].

3.2. Parents

Mothers (n=11) and a father (n=1) were included in the present study. All of them were present during the child's bowel cleansing prior to colonoscopy. Parents who understood and spoke the Swedish language with children younger than 18 years of age who had undergone their first elective colonoscopy performed using a PEG-based regimen were enrolled. The interviews took place in the family's home or in a private room at the hospital [11].

3.3. Data Analysis

All interviews were read and reread for this study several times in order to get a sense of the entirety. When several common areas of experience which could provide answers to the aim were identified, the interview text was sorted into four *content areas*: experiences related to the colonoscopy; experiences related to bowel cleansing; experiences related to symptoms, and views about the future. Then the text about the experiences of children and parents of bowel cleansing was extracted and

compiled in one area, which constituted the unit of analysis. Content was then divided into meaning units which were subsequently condensed and coded. The manifest content was found after all codes were compared based on differences and similarities and sorted into sub-categories and categories. Finally, the categories were reanalysed until the latent content which presented as a theme was found.

3.4. Ethical Considerations

Ethical approval was granted by the Regional Ethical Review Board in Lund (Ref. No. 2011/155 and Ref. No. 2012/ 186).

4. FINDINGS

The results were presented as one theme: *The children's and parents' perspective of bowel cleansing*. The results of the present study show both similarities and differences between children's and parents' experiences of a child's bowel cleansing prior to colonoscopy using PEG as a laxative. The bowel cleansing procedure consists of, for example, a diet regime before laxative intake, blood tests before and after laxative as well as laxative intake. However, all informants agreed that laxative intake was the most challenging for both, and these negative experiences reflects the entire procedure.

The Children's and Parents' Perspective of Bowel Cleansing

A prominent content area in the interviews related to the expectation prior to child's bowel cleansing. The parents described that they were aware of the importance of a clean bowel for examination while most of the children tried to find methods to ease their passage through the process and did not think about the risks of an unclean bowel. Nearly all of the children expressed that they did not understand why they had to undergo bowel cleansing. For the parents this part of the procedure was vital and they did everything possible for the child to drink the laxative with minimum stress. They understood that an unclean bowel could entail repeating the procedure and awaiting for potential treatment. The narratives of both children and parents revealed difficulties with this part of the procedure which was experienced as trying. The children and parents agreed that laxative intake was the most difficult part of bowel cleansing prior to colonoscopy because of the large volume of bad tasting laxative which the child must intake. Regardless of the information about the cleansing process, the children did not feel

confident about the procedure and they felt that they were forced to undergo cleansing. Even if the procedure was inconvenienced, the children hoped to manage used the wishful thinking and self-pep. Both the children and parents reported a feeling of loneliness during the bowel cleansing. While children expressed their unwillingness to talk about their concerns with anybody, parents described that they wished and needed to talk to nurses or physicians during the procedure. All informants reported a similar feeling that nobody understood them and their situation. However, this feeling was based on different starting points. Children expressed that only those who had undergone the same procedure could understand their feelings and not their parents or nurses. On the other hand parents thought that the nurses in charge would take care of the child's bowel cleansing and the entire procedure, but the experience in reality was different. The parents' experience was that the staff was present for short periods when the child was informed about the procedure and when they checked the child's intake of laxative. Parents felt that nurses did not understand their position. They were forced to push the child to drink and thus they were afraid of children not receiving any support. Usually the parents experienced that their child perceived them as an enemy for the procedure which had to be done. However the children describe their parents as supported. Regardless of different views of the situation, the children felt support and were satisfied with fact that parents were with them.

The children were not willing to drink the laxative and they were even more reluctant to have a nasogastric tube which was offered as one option. The parents also thought that the tube may have cause more concern for the child and encouraged their child to take the laxative orally. The children described that they resaved information about the laxative, however they could not imagine that they would have to drink so much. It was not only children who could illustratively describe the difficulties they had with intake of laxative. There were also some parents who tried drinking PEG who could describe both the child's experience and their own. The difficulties of intake could be expressed as the bad taste which made the "throat shut" and it was usually described that there was a sensation of "a lump in the throat". Parents agreed that they believed that the laxative would not cause concerns for the child,

which had later proved to be the hardest part of the bowel cleansing process. However, the parents were aware of the importance of bowel cleansing for a successful colonoscopy while most of the children did not understand why it was so important. While the parents described their struggle to make the child drink the prescribed amount of laxative, the children did everything to avoid drinking it, which was expressed by one parent as that: *“It felt like we were on two different sides and not together as we used to be”*.

5. DISCUSSION

The present study was conducted with the help of experiences of children and their parents and to the best of my knowledge this is the first time a comparison has been made of parents' and children's experiences of the bowel cleansing procedure using PEG as a laxative. The perspective of patients and families were earlier recognised as one important indicator of quality of care [24] and in the present study both children and parents reported that they experienced bowel cleansing as difficult and stressful, an indicator of deficient quality of care. This result implies a need for nursing interventions to reduce this negative development.

The results of this study show that the parents and children have negative experiences of the procedure but there are differences that are important to recognise for planning this procedure in the future. It was known from previous studies that children's and parents' views of the same situation can be based on different starting points, which may have a negative impact on the child [6]. The differences between these perspectives are also a reason for some researchers pointing out the importance of the child's perspective (child's own voice) in health care [5,6]. An important contributory factor to the discrepancy between these experiences in the current study is probably the fact that children only refer to problems they experience currently, while their parents often have a broader perspective. There may be a risk if only one of these perspective is used when bowel cleansing before colonoscopy is planned. Bowel cleansing with PEG was experienced as the most difficult part of the procedure by both children and parents and this result is in accordance with previous quantitative studies [20, 21, 22, 23]. These quantitative studies show difficulties with PEG intake based on a large volume and bad taste, however this study also

shows that children were not psychologically prepared for this procedure. They received information about PEG intake but it was perhaps insufficient and this could contribute to the negative experiences of children. It is well-known that children need to be well-prepared psychologically to minimise stress and anxiety [25], however in this study according of the child and parents rapport they were only informed about the procedure and not really prepared on it. Children did not ask many questions which could mislead staff to interpret that everything was fine and that both the child and parent were ready for procedure. The current study shows not only similarities in these experiences. There were also differences between children and parents when they talked about the procedure. These differences are important to recognise, a fact which is also confirmed in previous research [5], the results of which show the importance of not forgetting the child's perspective in paediatric care.

While most parents had a clear picture of the risk of an unclean bowel, the children did not show the same level of understanding and saw the procedure as something they “must do” without really understanding why. The parents' role is to support the child [7, 11] but in this study they expressed that they could not help their child in the way they wanted and desired. Previous studies [26] found no evidence of there being an ideal bowel cleansing procedure for children and while awaiting for several evidence-based protocols to be tested and evaluated, we need to adapt the current procedure to the child's best interest. This study's results can increase understanding of the child's situation when they undergo bowel cleansing and can create opportunities for the child's psychological preparation to be adapted to the child in a better way.

The study's results also show that comparing experiences may have an important role in the planning of a more appropriate procedure for children using PEG prior to colonoscopy.

6. STRENGTHS AND LIMITATIONS

The strength of this study is both the children's and parent's experiences of bowel cleansing which provide a more complete picture of the procedure and allow identification of some important aspects which can facilitate this difficult procedure for children.

The informants in this study were asked to describe their experiences, however the children

were interviewed about their own experience of undergoing a colonoscopy, while the parents' experience was based on the experiences of their child undergoing a colonoscopy. Trying to compare these experiences can be considered as a limitation of the study, but it can also show the importance of having both perspectives as previous research has shown that both perspectives are important if we are to meet children's needs in paediatric care[5,6]. The interviews took place a few years before this comparison. It could have affected the findings, however this effect is deemed to play an insignificant part as PEG is still the recommended and most used laxative for children.

7. CONCLUSION

The findings from the recent study suggested that both the children's and parent's perspective need to be used when considering bowel cleansing prior to colonoscopy in children. The individual preparation for the child using for example visual illustration of the technical procedures can be one of the solutions used to optimise the procedure for children. Both the children and their parent need more support from healthcare staff during the procedure. Future research will be needed to confirm these recommendation.

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