

ORIGINAL PAPER

Assessment of acceptance of the Crohn's disease exclusion diet by children with Crohn's disease and their parents

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ABSTRACT

Introduction: Nutritional therapy based on exclusive enteral nutrition or partial enteral nutrition together with the Crohn's disease exclusion diet (CDED) is a treatment option for inducing remission in children with Crohn's disease. The study aimed to evaluate the acceptance of the CDED by children with Crohn's disease (CD) and their parents.

Material and methods: The data were collected using an original questionnaire between April 2022 and March 2025. The study included 46 children with CD aged 7–18 and 59 parents.

Results: Sixty-one percent of parents and 52.2% of children have consulted a dietitian about the diet. Parents (69.5%) and children (58.7%) also use relevant apps. Most patients accepted the diet, but some needed more time. Thirty-nine percent of parents and 34.8% of children responded that other family members also eat meals according to the CDED. Half the adults said that products are more expensive and need more preparation time than the previous diet. Only 21.7% of CD patients admit that they strictly adhered to the CDED. Children with CD were forced to give up going to restaurants (60.9%) and going on school trips (34.8%). Children also experienced dislike from their peers. Fifty-nine and three tenths percent of parents admitted they gave up going to restaurants with their children because of the diet.

Conclusions: The Crohn's disease exclusion diet is generally well tolerated by paediatric patients with CD and their parents; though its implementation may be accompanied by psychosocial challenges. These include stigmatisation among peers, parental concerns regarding control of food intake outside the home, and the difficulties children face when eliminating favourite foods. Such factors should be considered when supporting families in long-term dietary management.

KEY WORDS:

children, inflammatory bowel disease, Crohn's disease exclusion diet (CDED).

INTRODUCTION

Crohn's disease (CD) is an inflammatory bowel disease that can affect any part of the digestive tract. Intestinal lesions are discontinuous, and inflammation is typically transmural [1, 2]. Treatment strategies for CD in children vary according to the extent and activity

of the disease. The objective of the treatment is to achieve remission. Patients at low risk of a complicated disease course should be induced into remission using exclusive enteral nutrition (EEN). If EEN is not an option, then corticosteroids are the next choice [3, 4]. The European Crohn's and Colitis Organisation (ECCO) recommendations for the treatment of CD indicate that although

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corticosteroids are effective in inducing remission, they are also associated with numerous effects that can negatively impact growth in children. Due to the high morbidity and mortality, steroids should never be used for maintenance therapy [3]. Due to the difficulties in implementing EEN in children, partial enteral nutrition (PEN) and the Crohn's disease exclusion diet (CDED) have been introduced. It has been observed that the CDED not only induces remission but may also help to maintain it [5]. Patients at high risk of a complicated disease course should be treated with anti-tumour necrosis factor agents from the outset to induce and maintain remission of CD.

According to the ECCO and European Society for Paediatric Gastroenterology, Hepatology and Nutrition guidelines [6], EEN should be chosen as a first-line therapy for induction treatment for children with mild-to-moderate CD. Exclusive enteral nutrition is a fully liquid formula diet administered for 6–8 weeks. Exclusive enteral nutrition has been proven more effective than corticosteroids in achieving mucosal healing – a meta-analysis by Yu *et al.* [7] found that steroids and EEN had a similar effect on the 1-year relapse rate.

The use of EEN in the induction of remission has been well-documented. However, its benefits extend beyond this, encompassing a range of additional outcomes, including mucosal healing, enhanced growth and nutrition, and improved bone mineralisation, accompanied by reduced resorption. Moreover, it has been demonstrated that using EEN induction before surgery has a favourable impact on postoperative outcomes [6, 8]. Despite these advantages, the use of EEN is limited by patients' poor palatability and lifestyle restrictions [9].

In children with low-risk CD who have achieved remission, PEN may be used to prolong the remission period. Partial enteral nutrition is initiated following successful EEN and involves providing a portion of the diet through a specialised nutritional formula. Using PEN has led to inflammation resolution, reduced mucosal inflammatory cytokine levels, and a decreased frequency of disease relapse, including postoperative recurrence following bowel resection. The greatest effectiveness of this therapy is observed when it is used as a short-term bridge between other therapeutic modalities [3].

In accordance with the European Society for Clinical Nutrition and Metabolism (ESPEN) guidelines from 2023, it is recommended that consideration be given to the use of CDED with PEN as an alternative to EEN for achieving remission in paediatric patients with mild-to-moderate CD. The Crohn's disease exclusion diet with PEN appears to be as effective as EEN in inducing a rapid clinical response, but is better tolerated. In a recent study by Ma *et al.* [10], the highest clinical remission rate and tolerance was associated with CDED + PEN among the various dietary therapy strategies that were evaluated in active paediatric CD patients. Never-

theless, there is a lack of data on the long-term effectiveness of elimination diets and the potential risks associated with nutritional deficiencies or eating disorders resulting from their prolonged use [11].

The Crohn's disease exclusion diet is a more convenient dietary therapy – the recent ESPEN guidelines recommended considering CDED as an alternative to EEN for adults. For patients who are difficult to treat and for whom biological treatment has failed, a therapy based on an exclusion diet can restore remission [12].

The Crohn's disease exclusion diet aims to avoid food that hurts the microbiome and the barrier's integrity, which are important preclinical markers of disease susceptibility [13].

The Crohn's disease exclusion diet is a therapeutic approach that eliminates foods with a detrimental impact on the gut microbiome and intestinal barrier, and is combined with 50% PEN. It has been observed that the CDED is effective in inducing remission and reducing inflammation, while demonstrating better tolerability [4, 14, 15]. The Crohn's disease exclusion diet comprises a delineated catalogue of authorised and proscribed foodstuffs, the effect of which on the gut microbiome has been determined. The diet under consideration should consist of five mandatory components: dietary fibre from fruits and vegetables, and substrates for short-chain fatty acids. By contrast, it is notable that animal fats, dairy products, gluten, and emulsifiers are excluded [14, 16] (Table 1).

The study aimed to evaluate the acceptance of the CDED by children and their parents.

MATERIAL AND METHODS

The analysis included questionnaire responses from 46 patients aged 7–18 (mean age 13.0 ± 2.99) diagnosed with CD and following the CDED, as well as from 59 parents of children aged 7–18 years on the CDED (mean age of the children being 13.46 ± 3.11). The data were collected between April 2022 and March 2025. Participants were eligible if they were ≤ 18 or a parent of a patient aged ≤ 18 and used the CDED between April 2022 and March 2025 or previously.

The exclusion criteria were: lack of consent to participate in the study or lack of questionnaire completion.

Data were collected using an original, anonymous questionnaire designed by the authors. Due to the lack of a properly validated questionnaire, we used a non-validated one that was created explicitly for this study. Due to the lack of known studies specifically focusing on the acceptance of the CDED by paediatric patients with CD, the development of the questionnaire was based on observations and conversations with children and the parents of children adhering to the diet. Based on this, the main thematic areas were identified: sources of knowledge about the diet, use of relevant applications, children's

TABLE 1. A comparison of exclusive enteral nutrition, partial enteral nutrition and Crohn's disease exclusion diet [3, 5, 14]

EEN	PEN	CDED
Consumption of a liquid medical formula as the sole food source	A diet in which a portion of daily caloric intake is provided through a specialised nutritional formula	A whole-food-based diet that excludes components detrimental to the gut microbiome and intestinal barrier, combined with PEN
Typically 6–8 weeks	Used as a short-term bridge between EEN and CDED	Three phases: • stage 1: 6 weeks – elimination diet + 50% PEN • stage 2: 6 weeks – reintroduction of selected foods + 25% PEN • stage 3: maintenance phase – continued for ≥ 9 months (target diet) + 25% PEN
Induction remission in patients with mild-to-moderate CD who are motivated to adhere to dietary therapy and prefer to avoid corticosteroids	Maintenance of remission and support of mucosal healing and growth	The process of reducing inflammation can be achieved through the exclusion of pro-inflammatory dietary components, with the concomitant restoration of microbiome balance
Effective in inducing remission and mucosal healing; similar relapse rate to corticosteroids at 1 year	Shown to reduce relapse rates, improve endoscopic indices, and enhance growth parameters (height, weight Z-scores)	Effective in inducing and maintaining remission; better tolerated than EEN; reduces inflammatory markers and supports sustained remission
Often limited by poor palatability and discomfort from the nasogastric tube; some children experience nausea or loose stools initially	Better tolerated than EEN; adherence depends on formula acceptance	Generally well tolerated; allows inclusion of selected whole foods, improving adherence

CD – Crohn's disease, CDED – Crohn's disease exclusion diet, EEN – exclusive enteral nutrition, PEN – partial enteral nutrition

TABLE 2. Characteristics of patients according to parents' and children's reports

Parameters	Children (reported by parents, <i>n</i> = 59)	Children (self-reported, <i>n</i> = 46)
Gender of patients (% of girls)	59.3	45.7
Age of patients (years, mean ±SD)	13.46 ±3.11	13.75 ±2.99
Age of CD diagnosis (years, mean ±SD)	11.88 ±3.43	11.87 ±3.28
Age of starting the CDED diet (years, mean ±SD)	12.42 ±3.22	12.4 ±2.97

CD – Crohn's disease, CDED – Crohn's disease exclusion diet, SD – standard deviation

responses to diet implementation, adherence among other family members, meal preparation, compliance with dietary guidelines and psychological aspects. We did not ask about concomitant treatment because our focus was on the dietary approach to therapy. The questionnaire was available in two versions: one for patients under 18 with CD who are currently following or have previously followed the CDED, and another for parents of patients under 18 with CD who are currently following or have previously followed the CDED. The questionnaire included closed-ended questions with the option to provide open responses. As an extra source of knowledge, the ModuLife application, which is structured around the CDED, could be used by both patients and their parents.

The questionnaire was distributed in paper form, electronically *via* e-mail, through a link published on the Polish Association for Supporting People with Inflammatory Bowel Diseases "J-elita's" official Facebook page and website, and *via* a QR code available during the Association's meetings. Due to the voluntary nature of participation, lack of control over sample selection, and the relatively

small sample size, the study cohort may not be fully representative of the broader paediatric CD population.

Statistical analysis was performed using Python with the SciPy package, applying the χ^2 test. A significance level of $p < 0.05$ was adopted.

RESULTS

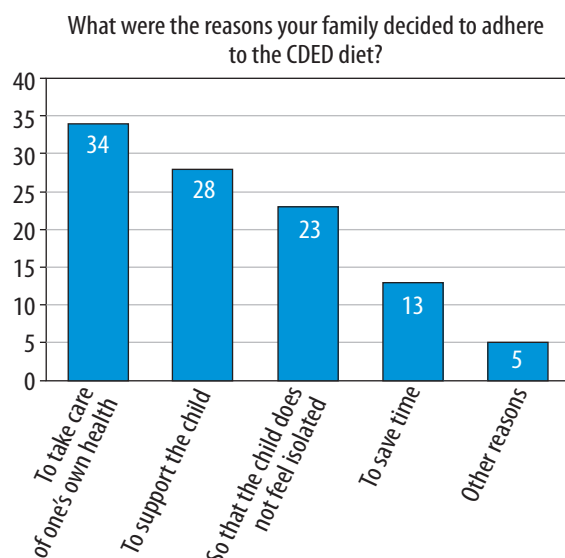
The characteristics of the study group are presented in Table 2. The group of parents and the group of children were two independent groups.

SOURCES OF INFORMATION ABOUT THE CROHN'S DISEASE EXCLUSION DIET AND ITS PURPOSE

Most respondents (96.6% of parents and 95.7% of children) reported that they learned about the diet from their physician. 59.3% of parents and 50% of children stated that the diet was introduced to induce remission, while the remaining 40.7% and 50% used the diet as an adjunctive therapy.

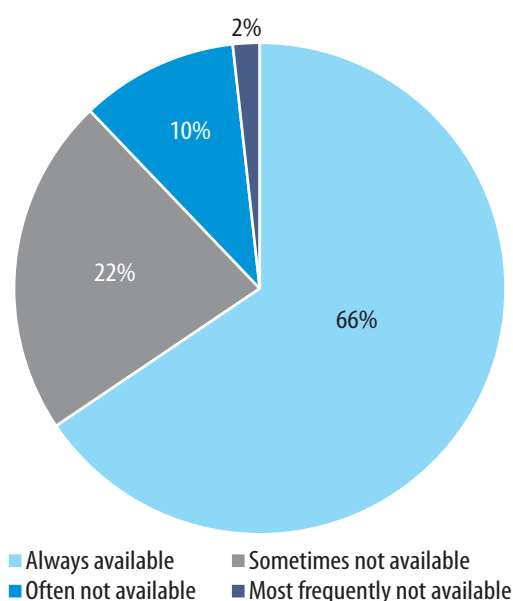
TABLE 3. Response of children with Crohn's disease to the introduction of the Crohn's disease exclusion diet

Parameters	Parents' responses (%)	Children's responses (%)
Accept the diet	44.8	26.1
Accept, but needed more time	29.3	43.5
Do not accept the diet	25.9	30.4

**FIGURE 1.** Reasons for using the Crohn's disease exclusion diet by family members of a child with Crohn's disease

COED – Crohn's disease exclusion diet

How would you evaluate the availability of food products used in the CEDED diet?

**FIGURE 2.** Availability of the Crohn's disease exclusion diet products in stores

COED – Crohn's disease exclusion diet

PROFESSIONAL DIETARY GUIDANCE FOR THE CROHN'S DISEASE EXCLUSION DIET

According to the parent survey, 61% reported that their child consulted a dietitian, and 35.6% indicated continuous care. In the child survey, 52.2% reported that they visited a dietitian, and 28.3% were under constant care. Parents were also asked why their child was not under the care of a dietitian. The most common responses were that using an app, the internet, or a doctor's guidelines was sufficient. Parents also reported difficulties finding a properly qualified dietitian or mentioned that the doctor did not suggest consultation.

USE OF DIGITAL APPLICATIONS

Patients and their parents could access the Modu-Life application, which is organised around the CEDED. The application was found useful by 69.5% of parents and 58.7% of children.

ACCEPTANCE OF THE CROHN'S DISEASE EXCLUSION DIET BY CHILDREN WITH CROHN'S DISEASE

We asked the respondents whether the patients accepted the diet and how they reacted to its introduction. According to 76.4% of parents, their child accepted the diet, even though some of them needed more time. The following results were obtained in the questionnaire completed by children: 69.6% of children reported accepting the diet; however, more than half of them indicated that more time was needed (Table 3). An analysis was conducted to compare the responses of both groups, revealing no statistically significant differences between them.

ADHERENCE TO THE CROHN'S DISEASE EXCLUSION DIET BY OTHER FAMILY MEMBERS

The Crohn's disease exclusion diet was used not only by children with the CD, 39% of parents and 34.8% of children responded that other family members also followed the recommendations. The most frequently reported reasons in both the parent and child groups were the desire to support the child so they would not feel alone and the intention to take care of their health by following a healthy diet. Parents also pointed out that preparing separate meals took too much time (Figure 1).

MEAL PREPARATION

Half of the surveyed parents noticed that the diet was more expensive than the previous diet and that they had to spend more time preparing meals. Sixty-six percent of parents stated that the products were consistently

available in stores (Figure 2). Forty-three and five tenths percent of children declared that they prepare their meals by themselves, and 90.5% of them stated that it took the same amount of time as before starting the diet.

ADHERENCE TO DIETARY RECOMMENDATIONS

Frequency of diet rule-breaking among children with CD is presented in Table 4.

PSYCHOSOCIAL ASPECTS OF FOLLOWING THE CROHN'S DISEASE EXCLUSION DIET

Thirty-two and two tenths percent of parents observed behavioural changes in their children. According to that, 73.6% of them sought support for their children through consultations with a physician, psychologist, or teacher, or by engaging in support groups. In comparison, 41.3% of the children reported changes in their behaviour and 29.4% of them decided to seek professional help. Also, 10.2% of parents and 15.2% of children reported that the child experienced social isolation and ridicule from their peers.

Thirty-four and eight tenths percent of children had to give up school trips, and 60.9% avoided eating out at restaurants. Fifty-nine and three tenths percent of parents also stopped eating out at restaurants with their children. Ultimately, we asked about the most challenging part of following the diet. For parents, it was a lack of control over their child's food intake when the child was away from home. For children, it meant having to give up their favourite meals. It was also difficult for both groups to give up going to restaurants.

DISCUSSION

In our study, we assessed the acceptance of the elimination diet in children with CD, used as a therapeutic strategy, both for induction and maintenance of remission. The implementation of elimination diets is consistently linked to several challenges, such as difficulties with adherence, financial costs, social restrictions, and their influence on quality of life (QOL). The economic aspects of dietary therapy should also be considered. The Crohn's disease exclusion diet is more expensive than a standard diet. Half of the surveyed parents noticed higher food shopping costs and spent more time preparing meals.

Following a strict diet usually means not being able to eat in public places with friends, making social life challenging. Children who are constantly on a special diet feel different from their peers, which enhances feelings of anger and jealousy, and causes lower compliance [17]. Of our respondents, 34.8% had to give up school trips, while 60.9% avoided eating out in restaurants.

The Crohn's disease exclusion diet, particularly in the initial phase, is an elimination diet that has the po-

TABLE 4. Violation of the Crohn's disease exclusion diet rules by children with Crohn's disease

Frequency of breaking CDED rules	Parents' responses (%)	Children's responses (%)
Never/always adhere to the diet	22.0	21.7
Several times per year	11.9	8.7
Once a month	20.3	21.7
Once a week	37.3	30.4
Every day	8.5	17.4

CDED – Crohn's disease exclusion diet

tential to result in nutritional deficiencies. Consequently, it is imperative to concurrently introduce PEN, which provides 50% of the caloric requirement in the first phase and 25% in the subsequent phases. Such restrictions require significant commitment from young patients and their families, highlighting the importance of working with a dietitian to ensure a balanced diet [14].

In the survey of respondents who are children, the most considerable difficulty experienced by respondents in using CDED is the necessity of relinquishing their favourite foods, which include highly processed foods such as fast food and sweets. Excluding many foods from their diet resulted in children refusing to eat meals in school canteens and taking part in birthday celebrations, which could contribute to their social exclusion among their peers. Parents found it very difficult to control their children's diet at school, indicating the need for cooperation with the school and more education for teachers and students. Many parents sought literature on diet to expand their knowledge and diversify their meals, but they encountered two significant obstacles: language barriers and the widespread availability of material in English. It is therefore imperative to promote this diet, as is the case with other diseases such as coeliac disease, diabetes, and kidney disease.

It has been demonstrated that diet may be associated with mental health. A correlation has been observed between unhealthy dietary patterns and worse mental health outcomes in children [18]. In this study the focus was on the relationship between mental health and overall diet quality. At the same time, there is a lack of research examining how adherence to a diet different from that of peers affects children's mental health. Our study identifies peer acceptance issues on the CDED, which may pose a risk of psychological difficulties. Children adhering to the CDED experience peer rejection and ridicule because of their dietary practices. Twelve and four tenths percent of children reported classmates' criticism. The crucial nature of being accepted by classmates for school-aged children means the provision of more school support is necessary.

A lack of peer acceptance is associated with an increased risk of psychological difficulties among children. Analyses showed that peer acceptance significantly predicted chil-

dren's academic achievements, underscoring the crucial importance of peer support [19, 20]. Empirical research indicates that children who experience peer rejection are particularly susceptible to the development of internalising problems, including symptoms of depression and anxiety [21–23]. The lack of social acceptance can be a problem for children during their school years and later in life and development. This highlights the need for education about chronic diseases and dietary regimens and the importance of promoting broader public awareness.

Strict dieting can increase anxiety levels and even trigger eating disorders, which adolescents are particularly susceptible to. The common symptoms of CD, particularly in paediatric patients, such as abdominal pain, nausea, 'picky eating', dysphagia, delayed gastric emptying and weight loss, are the same as those seen in avoidant/restrictive food intake disorder. Exclusion diets, such as the CDED, can remove patients' pleasure in eating and increase their fear of food due to the risk of relapse or exacerbation of the disease. This highlights the importance of identifying patients with a high level of anxiety, as they are at risk of developing a negative relationship with food and even an eating disorder, which can worsen compliance and their mental health [13].

Young patients may not adhere to treatment because they lack understanding of the illness and its treatment. They can only see its limitations, so support and education from parents, doctors, psychologists, dietitians, and friends can be crucial for their recovery. Only 57.1% of our respondents received dietary advice, and even fewer (32.4%) maintained regular contact with a dietitian, highlighting the constant need for further education. Programmes such as ModuLife (<https://access.mymodulife.com/User/Login>), which help with meal planning, offer expert advice and facilitate goal achievement, can be incredibly helpful for children and their families. Parents often opt out of seeing a dietitian, citing constraints such as limited availability and logistical challenges in accessing local professionals. This is why the smartphone-based platform ModuLife is being used. In an age of widespread technological access, this technology has given parents easy access to information about CDED and ready-made meal recipes. This enables them to monitor their children's adherence to the prescribed diet. The ModuLife programme has received a positive response from over half of the surveyed children and their parents.

Existing research on QOL focuses primarily on CD itself and its influence on daily functioning, without considering the role of diet. In a cohort study, Wijers *et al.* [24] evaluated patients' experiences adhering to the CDED and their compliance with dietary recommendations in children and adults. The findings indicated that patients were satisfied with the effects of the diet and expressed willingness to recommend it to others. Nonetheless, the study underscored important limitations, namely the small sample size and the retrospec-

tive assessment of patients' experiences after completion of therapy, which may have resulted in an overestimation of the outcomes. This study observed that the highest rate of diet discontinuation occurred during the second phase. Longer adherence to the diet was associated with greater compliance with recommendations and motivation to continue the dietary regimen. In order to estimate adherence to dietary recommendations, we inquired as to the frequency with which patients contravened CDED guidelines. The results demonstrated that 21.7% of patients exhibited consistent compliance but there is a lack of validated tools to accurately assess dietary adherence.

Only a few studies in the literature examine the impact of the CDED on QOL, particularly in paediatric populations. Existing studies focus on the effectiveness and safety of the CDED treatment, but do not include patients' acceptance of the diet. The recent study by Rohani *et al.* [25] shows the importance of dietary strategies such as CDED and PEN in paediatric CD management from the microbiome perspective proving their anti-inflammatory effect. This suggests that the patient-centred approach to this topic has largely been overlooked and warrants further investigation [10, 13, 24].

LIMITATIONS

We acknowledge the limitations of this study, including the relatively small number of volunteers, which means that the results may not fully represent the broader paediatric CD population. Our focus was mainly on the current feelings of paediatric patients and their parents while using CDED, rather than on retrospective feelings. We prioritised the impact on daily life and mental health of teenagers, as these factors directly impact compliance. Another limitation is undoubtedly the failure to consider patients' use of concomitant pharmacological treatment and disease activity. We also did not consider the duration of CDED use or why CDED was chosen over EEN/PEN. The data were collected using a questionnaire that was specifically designed for this study, but not validated.

CONCLUSIONS

The present study is asserted to have shed light on a clinically important yet previously inadequately researched subject, i.e. the CDED, which plays a significant role in the treatment of patients with mild-to-moderate CD. The study is based on data from patients who expressed gratitude for the opportunity to share their views. This will have a significant impact on the utilisation of this treatment in clinical practice. Furthermore, the perspectives of both patients and their parents were discussed. In conclusion, although most children and their parents adapt well to the CDED, adherence often requires additional time and considerable effort. Continuous support from dietitians, digital tools, families,

and healthcare providers is essential to ensure long-term compliance. Parents frequently report difficulties in controlling food intake outside the home, leading to restrictions in social activities such as eating out. Strict dietary adherence demands significant sacrifices and affects the daily life of the entire family. At the same time, children may also experience peer rejection or social exclusion, with potential consequences for their psychosocial development and mental health. These challenges highlight the need to raise broader public awareness of therapeutic diets used in chronic disease management.

DISCLOSURES

1. Institutional review board statement: The study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Committee of the Medical University of Silesia.
2. Assistance with the article: None.
3. Financial support and sponsorship: None.
4. Conflicts of interest: None.

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