

Short Communication



Exclusive Enteral Nutrition for the Treatment of Pediatric Crohn's Disease: The Patient Perspective

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Conflict of Interest

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ABSTRACT

Crohn's disease (CD) is a chronic, incurable and relapsing disease involving any part of the gastrointestinal tract and exclusive enteral nutrition (EEN) is first-line therapy. Few studies have examined the patient experience of EEN. The aim of this study was to assess the child's experiences of EEN, to identify problematic themes and understand the child's mindset. Children with CD who previously completed EEN were recruited to complete a survey. All data were analyzed using Microsoft Excel and reported as N (%). Forty-four children (mean age 11.3 years) consented to participate. Sixty-eight percent of children reported limited formula flavors as the most challenging aspect and 68% of children identified 'support' to be important. This study highlights the psychological impact of chronic disease and its therapies on children. Providing adequate support is essential to insure EEN is successful. Further studies are required to determine psychological support strategies for children taking EEN.

Keywords: Inflammatory bowel disease; Crohn disease; Enteral nutrition; Pediatrics; Child psychology

INTRODUCTION

Crohn's disease (CD) is a chronic, incurable and relapsing disease involving any part of the gastrointestinal tract [1-5]. Incidence is rising globally; however, disease aetiology is still not completely understood. The current consensus is that genetic predisposition combined with altered intestinal microflora and a dysregulated immune response leads to the development of chronic inflammation and, ultimately, CD in some individuals [2,4,6,7].

The goal of therapy for children with CD is to induce and maintain remission [2,6]. Several treatment pathways for remission induction in pediatric CD are available, with exclusive enteral nutrition (EEN) as the recommended first-line therapy [8,9]. EEN involves a 6–8-week period of a liquid-only diet using a polymeric formula either orally or via a naso-gastric feeding tube. For children with CD, EEN is reported to be as effective in inducing remission as corticosteroids (CS); however, it provides the additional benefits of much higher rates of mucosal healing (MH), normalization of inflammatory markers, enhanced growth, repletion of micronutrient deficiencies and obviating the need for CS [10]. The restoration of normal growth is a long-term therapeutic target for pediatric CD [11] as the inflammatory process

can impact adversely upon a child's linear growth potential [2,7]. Long-term outcomes are also improved when remission is induced via EEN, as MH is crucial for long-term remission, resulting in lower relapse rates than in active endoscopic disease [12,13].

Very few studies have examined the patient experience of EEN. Children and adolescents reported that they feel excluded from family meals and social occasions connected with food and eating due to the restrictions within the EEN protocols [14]. Moreover, they feel isolated, different or ostracised from their peers [15,16].

Following induction treatment, the manipulation of diet through food avoidance or restriction is common in children with inflammatory bowel disease (IBD) [17-21]. Navigating nutrition is reported as a lifelong struggle, which decreases the enjoyment and pleasure associated with food [17,18]. Most patients who complete EEN have not received advice from a health care provider regarding these dietary changes, which may have nutritional consequences [18,20]. The aim of this study was to assess the child's experiences and attitudes towards EEN to identify problematic themes and better understand the child's mindset.

MATERIALS AND METHODS

Study participants

Children aged 5-17 years of age with a diagnosis of CD [22] who had previously completed a course of EEN were recruited to complete this survey. EEN was defined as the consumption of a polymeric formula calculated to meet one hundred percent of the child's nutritional requirements for their age for the duration of eight calendar weeks. No other concomitant foods or fluids were allowed except for still water. Children with concurrent dietary restrictions (e.g., gluten free diet for coeliac disease), without a diagnosis of CD or undergoing an EEN course currently were excluded.

Maintenance enteral nutrition (MEN) was defined as the consumption of polymeric formula calculated to achieve thirty percent of the child's nutritional requirements for their age in addition to the child's habitual dietary intake [8]. Participants' anthropometry and disease activity scores were calculated using the pediatric Crohn's disease activity index at the time of the child's last gastroenterology review. Disease location using the Montreal classification and medication therapies were obtained from the child's medical notes. Informed consent was obtained at the time of the child's routine IBD clinic appointment where they completed the survey after their scheduled appointment with the pediatric gastroenterologist.

EEN survey

The 9-question survey was developed by the pediatric gastroenterology dietitian (available on request), and was beta tested by five children with IBD and two dietetic colleagues prior to distribution. The readability score of the survey was 9.8 years, so children under the age of 10 were asked to complete the survey with the help of their parent if required. It included a combination of multiple-choice questions, Likert-scale questions which asked the child to rate their preference and free-text questions to qualitatively assess the child's experience.

Statistical analysis

All data were analyzed using Microsoft Excel 2018 (Microsoft) and reported as N (%). Qualitative data were reported verbatim and analyzed using thematic analysis [23]. Spearman's nonparametric correlation coefficient test was completed to determine any relationships between successful EEN treatment scores and baseline characteristics, disease location, disease scores and medical therapies. Results were considered statistically significant at the 0.05 level.

RESULTS

Population of children with CD

A total of 44 children with CD consented to participate in this study. None of the respondents were excluded from analysis and all completed the EEN survey (**Table 1**). Twenty (45.5%) of the 44 children were female. The mean age of participants was 11.3 years (range, 5.4–16.5 years), with a mean time since diagnosis of 3.3 years. Ten (22.7%) children had completed more than one course of EEN. Fifty-five percent of children were taking MEN at the time of completing this survey. There were no significant relationships between any baseline characteristics, disease location, disease scores or medical therapies and participants' use of EEN ($p>0.05$ for all).

All patients received fortnightly gastroenterology clinical outpatient review with the multidisciplinary team during their course of EEN. The clinical dietitian reviewed all children or their parent/guardian via telephone on the weeks between the outpatient clinic review.

Table 1. Participant characteristics and demographics

Variable	Crohn disease (n=44)
Age (yr)	11.3 (5.4–16.5)
Sex (female)	20 (45.5)
Weight z score	0.39±1.33
Height z score	0.56±1.06
BMI* z score	-0.09±1.32
Nutritional risk	
Low risk	44 (100.0)
Medium risk	0 (0.0)
High risk	0 (0.0)
Disease location (montreal classification)	
L1 (terminal ileum)	15 (34.1)
L2 (colon)	8 (18.2)
L3 (ileocolon)	26 (59.1)
L4 (upper GI)	5 (11.4)
P (perianal involvement)	4 (9.1)
Years since diagnoses (yr)	3.3 (1–6)
PDAI score	
<10 remission	36 (81.8)
10–25 mild	8 (18.2)
25–40 moderate	0 (0.0)
>40 severe	0 (0.0)
Concurrent therapies	
Infliximab	6 (13.6)
Corticosteroids	0 (0.0)
Thiopurines	14 (31.8)
Maintenance enteral nutrition	24 (54.5)

Values are presented as mean (range), number (%), or mean±standard deviation.

BMI: body mass index, GI: gastrointestinal, PDAI: pediatric Crohn's disease activity index.

*The WHO standard indices, nutritional risk as defined by the WHO BMI z-score aged 5–19 years.

Participant survey responses

Survey responses showed that half of participants 'struggled' to complete EEN while 36% found EEN to be 'easy' (Table 2). The most difficult aspects of completing EEN were the lack of polymeric formula flavors as reported by 68% of children followed by 23% reporting that they 'disliked' the taste of the formula and 9% struggled with 'food cravings'. The most preferred flavor of formula was chocolate (50%) and the least preferred was banana (9%). Fifty percent of children reported 'more energy' as being the most notable symptom to improve while completing EEN.

Table 2. EEN qualitative patient survey results

Questions	Value (n=44)
1. What was your experience with EEN?	
a. I struggled	22 (50.0)
b. Very difficult	2 (4.5)
c. Easy	16 (36.4)
d. Very easy	4 (9.1)
2. What was the most difficult aspect?	
a. Lack of flavor variety	30 (68.2)
b. Disliked the taste	10 (22.7)
c. Food cravings	4 (9.1)
3. Which polymeric formula did you use?	
a. Fortisip	26 (59.1)
b. Ensure plus	24 (54.5)
c. Fotini	8 (18.2)
4. What flavour was the most preferred?	
a. Berry	10 (22.7)
b. Chocolate	22 (50.0)
c. Vanilla	8 (18.2)
d. Banana	4 (9.1)
5. How many times have you completed a course of EEN	
a. Once	34 (77.3)
b. More than one time	10 (22.7)
6. What was the most notable improvement of completing EEN?	
a. More energy	24 (54.5)
b. Symptom relief	8 (18.2)
c. Reduced nausea	12 (27.3)
7. If required, would you complete another course of EEN?	
a. I would struggle but yes	28 (63.6)
b. Very likely	6 (13.6)
c. Never again	4 (9.1)
d. Unsure	6 (13.6)
8. Are you currently taking any maintenance enteral nutrition?	
a. Yes	26 (59.1)
b. No	18 (40.9)
9. What would you tell other children with Crohn disease that would help them through EEN?	
Free text comments	
a. Support is the biggest advantage	
b. Being reviewed often by the medical team helps keep you on track	
c. Get school on board	
d. Get your family to participate or to give up their favorite foods during your course of EEN	
e. Freeze the drinks into paddle pops or heat the chocolate drinks into hot chocolates	
f. It is more a mental game than a physical struggle	
g. It will help you, so stay positive!	
h. You may get your symptoms back once you stop EEN and start to eat normal food again.	
i. The better I felt, the bigger my appetite got, so be prepared to drink a lot more drinks than your requirements.	
j. Don't be afraid to tell you friends about your IBD and why you are doing EEN because a real friend will support you through the hard times.	
k. Ask your parents to buy you something special when you finish EEN because you will have something to look forward to.	

Values are presented as number (%).

EEN: exclusive enteral nutrition, IBD: inflammatory bowel disease.

Sixty-four percent of children reported they 'would struggle' to complete another course of EEN in future but that they would still complete it if required. In contrast, 9% reported they would 'never' repeat another course of EEN.

A total of nine free text responses were recorded (**Table 2**). The most common theme identified within the free-text responses was the importance of 'support', as reported by 67% of participants.

DISCUSSION

This study identified several interesting themes regarding children's attitudes and opinions of their experience with EEN. These themes highlighted the common challenges that children face when completing EEN, which disease symptoms are typically the first to improve, and participants' candid advice to their peers with CD who may also require treatment using EEN. This was the first study to provide a child's voice to the intervention of EEN for the treatment of CD.

Not surprisingly, half the children reported that they struggled to complete the 8-week course of EEN; however, 36% found it to be an easy process. The reported lack of flavor variety was reportedly the main reason for struggling, followed by a dislike for the taste of the polymeric formula and food cravings. Despite the high percentage of children who struggled to complete EEN, 64% still reported that they would complete another course of EEN if indicated. In addition, 59% of children who participated in this study were taking ongoing maintenance enteral nutrition at the time of completing this survey. This suggests that whilst children do struggle to complete EEN during the 8-week treatment phase, the benefits of EEN outweigh the decision to cease the treatment.

Similarly, to a prior study, the most notable improvement in symptoms was a reported increase in energy [24], followed by reduced nausea and symptom relief. Improved energy is likely due to the combination of mucosal healing and decreased inflammation resulting in an increased appetite and improved nutrient absorption, increased caloric intake and a concentrated quantity of micronutrients in the formulae.

Support is likely a main determinant of a child successfully completing treatment as suggested by the free text survey responses. Moreover, the multidisciplinary team and the dietitian provided weekly review during the child's EEN which likely attributes to a successful and more compliant course of EEN. Statements that illustrate the importance of support during EEN are "Support is the biggest advantage", "Being reviewed often by the medical team helps keep you on track", "Get school on board", "Don't be afraid to tell your friends about your IBD and why you are doing EEN because a real friend will support you through the hard times" and "Get your family to participate or to give up their favorite foods during your course of EEN". Thus, it is essential to listen to the child, to be aware of the psychosocial impact that chronic disease has on a young person, and to provide them with the support they reportedly need to guarantee a successful treatment outcome.

Nutrition plays an important role in etiology and treatment of children with CD. Children with active disease may experience anorexia, early satiety and impaired nutrient absorption which cumulatively impair the overall nutritional status and adversely impact upon normal growth and development [25]. Moreover, children with CD have poorer food-related quality

of life compared to their sibling and a control group [26] indicating the psychosocial impact of chronic disease [26].

Disease symptoms affect the psychological well-being of children with CD by affecting their social confidence [27]. Furthermore, children have difficulty maintaining their social activities due to both their disease symptoms and the negative psychological impact of their chronic disease [28]. Moody et al. [29] reported 60% of children are often unable to leave the house, 60% of children have regular school absences, 40% are concerned about going on holidays, 70% are not able to participate in routine sports, and 50% are unable to regularly be social. One child in this study advised that completing EEN “is more a mental game than a physical one” and another child recommends to her peers that “it will help you, so stay positive!”. This further illustrates the mental challenge of completing EEN and the value of acknowledging and discussing this with any child about to complete EEN, so that they can overcome and persevere during treatment.

This study had several limitations including the limited number of participants and their variable age at the time of completing this survey. Moreover, the time of finishing EEN and completing this survey was variable between children, and there was also no analysis completed to assess whether treatment efficacy affected a child's perception of EEN. A further limitation is that no analysis was completed to assess the reasons why a child's EEN was not successful. Lastly, this study was completed retrospectively and included qualitative analysis which can be open to interpretation. The strengths of this study are that this is the first study to provide the patient's voice to the EEN intervention and all participants were treated in a standard protocol at the same tertiary center.

In conclusion, this study reports the perspectives of a group of NZ children about treatment with EEN for their CD. It highlights the impact that both chronic disease and its respective treatment therapies have on a child's mental well-being, and the need to provide support in all areas of their lives while they are enduring EEN to make the treatment more successful and tolerable. Further studies are required to assess strategies that may provide the best support for children taking EEN and to help alleviate the psychosocial impact of CD as they grown into adulthood.

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