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Dietary beliefs in children and adolescents with inflammatory bowel disease and their parents

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Dietary Beliefs in Children and Adolescents with Inflammatory Bowel Disease and their Parents

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ABSTRACT

Objectives: Patients with inflammatory bowel disease (IBD) may have diet-related beliefs that lead to restrictive dietary behaviours. This study aimed to evaluate dietary beliefs in young patients with IBD and their parents and the presence of restrictive behaviours.

Methods: A questionnaire regarding dietary beliefs was administered to IBD patients aged 8-17 years and their parents. A Food Frequency Questionnaire was administered to patients with IBD and a peer control group.

Results: Seventy-five patients and 105 parents were interviewed. Twenty-seven (36%) patients and 39 (37.1%) parents believed that dietary modifications could control the IBD course.

Twenty-five (33.0%) patients and 33 (33.0%) parents believe that some dietary components can prevent relapse or improve symptoms (mainly abdominal pain and diarrhoea), while 36 (48%) patients and 60 (60.0%) parents believe that some foods can induce or worsen symptoms during an IBD flare.

Patients believe that milk, dairy, fried and spicy foods, sweets and carbonated drinks could have a negative effect on IBD while fruits, vegetables and rice could have a positive impact. Parents believe that fruits and vegetables have a negative effect.

Responses did not differ among patients classified according to IBD phenotype, activity status, or current therapies.

Compared to controls, young patients with IBD have reduced daily consumption of milk, lunch meat, raw and cooked vegetables.

Conclusions: About one-third of paediatric patients with IBD and their parents have dietary beliefs that lead to restrictive dietary behaviours.

Key Words: beliefs, children, diet, inflammatory bowel disease, parents

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What Is Known

- Diet is perceived as a very influential aspect of intestinal disorders.
- Patients with inflammatory bowel disease (IBD) may mistakenly correlate specific foods with worsening symptoms and adopt restrictive diets.

What Is New

- More than one-third of young patients with IBD and their parents believe that diet has a significant role in the course of IBD.
- Restrictive diets are believed to have a positive effect on IBD symptoms.
- Compared to peers, young patients with IBD have reduced daily consumption of milk, lunch meat, raw and cooked vegetables.

INTRODUCTION

Inflammatory bowel diseases (IBD), encompassing Crohn's disease (CD) and ulcerative colitis (UC), are multifactorial conditions induced by the interaction of environmental and genetic factors that leads to the dysregulation of the immune system.

Epidemiological studies suggest that diet may be one of the environmental factors capable of promoting the onset of IBD and influencing its course (1). The possible mechanisms include exposure to proinflammatory antigens, the interaction with the intestinal microbiota, the alteration of the gut permeability, and the imbalance of mediators of inflammation. The impact of diet appears to be greater in patients with CD, while there is less evidence for UC (2). The "westernized" diet, rich in milk and animal fats, v-6 polyunsaturated fatty acids, refined sugars, and proteins but poor in fruits and vegetables, has been found to have the strongest association with the development and the activity of IBD compared to other models of diet (1,3).

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To date, even if no single food substance has been identified as causative of IBD onset or relapse, a high intake of snacks, prepared meals, carbonated beverages, and sauces with low vegetables and fruit has been associated with a greater likelihood of CD development and a carnivorous pattern with UC development (4).

Diet is a fundamental aspect of people's daily living, and the knowledge of patients' dietary beliefs and habits is relevant for adequately planning possible interventions.

In 2020, the International Organization for the study of Inflammatory Bowel Diseases (IOIBD) provided expert opinion on diet for patients with IBD based on the best current evidence (5). However, patients could go to do-it-yourself practices based on their own beliefs or information obtained independently, with a possible risk of restrictive diets and nutritional deficits. It has been shown that more than half of adult patients with IBD modify their diet, placing restrictions on many types of food and avoiding milk, spicy food, fatty food, fruits and vegetables, alcohol, carbonated beverages, mainly to prevent relapses (6,7). A study involving paediatric patients in North America showed that dietary restrictions could also be observed in children with CD or UC (8).

While these data suggest that physicians' awareness of patients' beliefs may improve the quality of care, the available paediatric literature on this topic is still limited, and no data are available about parents.

The primary aim of this study was to evaluate the presence of diet-related beliefs in children and adolescents with IBD and their parents.

The secondary aim was to assess whether young patients with IBD had some dietary restrictions compared to a control group.

MATERIALS AND METHODS

The study was conducted at two paediatric care centres for IBD in the North-East of Italy between October 2019 and June 2021. Patients aged between 8 and 17 years diagnosed with IBD for at least six months and their parents were considered eligible and consecutively enrolled.

Exclusion criteria included known eating disorders, other diseases with dietary limitation (i.e., Coeliac Disease, Eosinophilic Esophagitis), or other physician-prescribed diets (i.e., low residue diet for strictures) at the time of enrolment.

The following demographic and clinical data were collected: sex, age at diagnosis of IBD, age at enrolment, type of IBD, localization and behaviour of IBD according to the Paris classification (9), nutritional status using the body mass index in accordance with gender and age and the z-score, clinical activity at enrolment defined by a Paediatric Crohn's Disease Activity Index (PCDAI) > 10 for patients with CD and the Paediatric Ulcerative Colitis Activity Index (PUCAI) > 10 for patients with UC.

Patients and parents were asked about their diet beliefs and habits with two questionnaires developed taking the surveys performed by Limbi (6) and Zallot (7) as a model. The questions and the possible answers addressed to patients and parents are reported in Tables 1 and 2, Supplemental Digital Content, *http://links.lww.com/MPG/C856*, respectively.

The questionnaire was given to the parent who accompanied the child on the visit. If both parents were present, the questionnaire was given to each parent.

A food frequency questionnaire was used to capture the patient's usual food consumption. Food classes have been divided as follows: gluten-containing cereals foods, gluten-free cereals, potatoes, red meat, white meat, cured meat, fish, raw and cooked vegetables, fresh fruits, dried fruit, legumes, milk and dairy product, egg, carbonated or sweetened drinks, sweets (including pastry, candies, chocolate). For each of these food classes, the frequency of consumption was assessed by dividing it into daily (at least once a day), weekly (at least once a week), monthly (at least once a month), annual (at least once a year), and total exclusion from the diet (never consumed during the year).

To compare the eating habits of IBD patients with the general population, a control group of children aged between 8 and 17 years with no gastrointestinal functional disorders or pathologies that do not require dietary treatment (i.e., reumathologic or immunologic conditions) was enrolled.

Statistical Analysis

Data were recorded in an electronic database, and the statistical analysis was carried out using the statistical analysis software Graph Pad and R (version n 3.5.0).

Continuous data are presented as medians with interquartile ranges (IQR) according to data distribution verified through the Shapiro Wilk-test of normality; categorical data are presented as absolute relative frequency and contingency tables.

To assess differences in responses according to disease characteristics and compare the parameters of interest between patients with IBD and controls, the Chi-square test or Fisher test was used for the categorical variables. The t-student or Mann-Whitney tests based on the parametric or non-parametric distribution were used to compare the continuous variables.

The Stuart-Maxwell-test for marginal homogeneity was used to assess the concordance between child-parent responses.

The statistical tests are 2-tailed, and the significance level was set for a value of p less than 0.05.

Ethical Considerations

Written and signed informed consent was obtained from the parents of the patients to join the study. The Ethics Committee approved the study protocol.

RESULTS

1. Patients' and Parents' Beliefs

All patients and parents who were asked to participate adhered to the study. Seventy-five patients, 66 mothers and 39 fathers were enrolled. The clinical characteristics of patients are reported in Table 1.

Complete responses of patients and parents are reported in Table 2 and Table 3, respectively.

Few patients and parents believe that dietary habits played a significant role in the onset of IBD.

Diet is believed to be more important than drugs in the treatment of IBD by 21.3% of patients and 24.8% of parents; about 35% of both believe that symptoms can be controlled by modifying the diet.

One third of patients and parents believe that eating some dietary components can prevent relapse or improve symptoms (mainly abdominal pain and diarrhoea) while 48% of patients and 60% of parents believe that eating some kinds of food can induce or worsen symptoms during an IBD flare.

White meat and rice are considered to improve symptoms and shorten relapses while milk and dairy, fried and very fatty foods, sweets and sugary drinks are considered to worsen symptoms and duration of relapse. Fruits and vegetables are thought to have a positive effect by patients and a negative effect by parents (Table 4).

IBD determined no effect on appetite and pleasure to eat according to half of the patients and parents.

TABLE 1. Patients' characteristics

Patients, n	75
Sex, n (%)	
Male	45 (60)
Female	30 (40)
Age at enrolment - years Median (IQR)	15 (13–17)
Age at diagnosis, years median (IQR)	11.6 (7.1–13.5)
IBD type	
CD	36 (48)
UC	38 (51)
IBD-U	1 (1)
Disease activity	19 (25)
Active disease, n (%)	
Remission, n (%)	56 (74)
Treatment at enrolment, n(%)	3 (4)
Partial enteral nutrition*	
Steroids	6 (8)
Aminosalicilates	34 (45)
Immunemodulators	17 (20)
Biologics	33 (44)
Thalidomide	5 (7)
Antibiotics	6 (8)
Previous exclusive enteral nutrition, n (%)	19 (25.3)
Previous surgery, n (%)	9 (12)
BMI, n (%)	
Underweight (<5th percentile)	1 (1)
Normal weight (> 5th and < 85th percentile)	59 (79)
Overweight (≥ 85th percentile)	10 (13)
Obese (≥ 95th percentile)	5 (7)

* Partial enteral nutrion used as an energy supplement while on a free diet.

About 60% of patients and 40% of parents report dietary changes after the IBD diagnosis. Almost all patients report not following a specific diet. Five percent of patients report a low-fibre diet while an equal proportion of parents believe their child is following a whole-grain or vegetarian diet.

About 10% of patients reported having social limitations.

No statistically significant difference was observed between patients' and parents' answers classified according to IBD phenotype, disease remission or activity status, or current therapies or comparing mothers' and fathers' answers (all *P*-values >0.05).

In the paired analysis, an inter-observer agreement between patients and parents was found for most of the answers. A significant difference emerged in the agreement of responses regarding the role of foods in preventing or promoting disease relapse.

2. Patients' and controls' dietary habits

One hundred and fifty controls were enrolled. The median age was significantly lower than that of patients with IBD (Table 1, Supplemental Digital Content, *http://links.lww.com/MPG/C856*).

The evaluation of the food diaries showed significant differences between patients with IBD and controls in the consumption of at least one serving per day of milk [25 (33.3%) patients versus 81 (54.0%) controls (*P* 0.004)], lunch meats [6 (8.0%) patients versus 30 (20.0%) controls (*P* 0.02)], and raw or cooked vegetables [30 (40.0%) patients versus 84 (56.0%) controls (*P* 0.03)].

Of the 80% patients who reported drinking milk even occasionally, 13.3% reported the use of lactose-free milk.

No significant differences were found for the consumption of gluten and other cereals derivates, dairy, eggs, fish, white ore read meat, fruits, sweets and beverages. (all p-values >0.05).

Dietary Counselling

More than 60% of patients and 50% of parents reported receiving nutritional advice from one or more sources: the paediatric gastroenterologist (52.1% patients, 67.3% parents), the general practitioner (27.11% patients, 36.5% parents), the nutritionist (12.5% patients, 21.1% parents).

For 39.5% patients and 46.1% parents, the source of information was journals, websites, or nonmedical figures (e.g. personal trainers, friends, other patients).

TABLE 2. The dietary beliefs of the paediatric patients with IBD

		Yes	No	I don't know
1	Do you believe that your diet has played a role in developing your disease?	8 (10.7)	57 (76.0)	10 (13.3)
2	Do you believe that diet has a more important role than drugs in managing your disease?	16 (21.3)	37 (49.3)	22 (29.3)
3	Do you believe you can control your intestinal symptoms by modifying your diet?	27 (36.0)	22 (29.3)	26 (34.7)
4	Do you believe that eating certain foods can prevent relapses or improve your symptoms in case of a relapse?	25 (33.3)	25 (33.3)	25 (33.3)
5	Do you believe that eating certain foods can promote relapses or worsen your symptoms in case of a relapse?	36 (48.0)	25 (33.3)	14 (18.7)
6	Do you believe IBD itself can change your hunger and pleasure in eating?	22 (29.3)	43 (57.3)	10 (13.3)
7	Have you modified your diet since the diagnosis of your IBD?	27 (36.0)	43 (57.3)	5 (6.7)
8	Are you following a specific diet?	4 (5.3)	70 (93.3)	1 (1.3)
9	Do you have a role in choosing what to eat?	41 (54.7)	27 (36.0)	7 (9.3)
10	Do you share the same menu as the other members of the family living under the same roof?	54 (72.0)	20 (26.7)	1 (1.3)
11	Do you refuse outdoor dining for fear of causing relapse?	7 (12.7)	47 (85.5)	1 (1.3)
12	Have you ever received any advice on your diet?	48 (64.0)	27 (36.0)	0
13	Would you be keen on receiving some nutritional advice from a professional experienced in the field?	41 (54.7)	18 (24.0)	16 (21.3)

TABLE 3. The dietary beliefs of parents

		Yes		No		I don't know	
		Mother	Fathers	Mothers	Fathers	Mothers	Fathers
1	Do you believe that diet has played a role in developing the IBD in your son/daughter?	6 (6.1)	2 (5.1)	46 (69.7)	24 (66.7)	16 (24.2)	11 (28.2)
2	Do you believe that diet has a more important role than drugs in managing the IBD of your son/daughter?	15 (22.7)	11 (28.2)	38 (57.6)	17 (43.6)	13 (19.7)	11 (28.2)
3	Do you believe your son/daughter can control his/her intestinal symptoms by modifying the diet?	25 (37.9)	14 (35.9)	24 (36.4)	13 (33.3)	17 (25.8)	12 (30.8)
4	Do you believe that eating certain foods can prevent relapses or improve your son/daughter's symptoms in case of a relapse?	26 (39.4)	9 (23.1)	20 (30.3)	8 (20.5)	20 (30.3)	22 (56.4)
5	Do you believe that eating certain foods can promote relapses or worsen your son/daughter's symptoms in case of a relapse?	30 (45.5)	16 (41.0)	15 (22.7)	10 (25.6)	21 (31.8)	13 (33.3)
6	Do you believe IBD itself can change your son/daughter's hunger and pleasure in eating?	22 (33.3)	17 (43.6)	42 (63.6)	18 (46.2)	2 (3.0)	4 (10.3)
7	Do you decide and prepare the food for your son/daughter's meals when he/she eats at home?	57 (86.4)	18 (46.2)	3 (4.5)	10 (25.6)	6 (9.1)	11 (28.2)
8	Have you modified your son/daughter's diet since the diagnosis of IBD?	26 (39.4)	14 (35.9)	39 (59.1)	25 (64.1)	1 (1.5)	0
8	Does your son/daughter share the same menu as the other members of the family living under the same roof?	49 (74.2)	34 (87.2)	15 (22.7)	5 (12.8)	2 (3.0)	0
9	Is your son/daughter following a specific diet?	4 (6.1)	2 (5.1)	62 (93.9)	37 (94.9)	0	0
10	Have you ever received any advice on your son/daughter's diet?	34 (51.5)	18 (46.2)	32 (48.5)	21 (53.8)	0	0
11	Would you find it helpful to receive dietary advice for your child's diet from a professional experienced in the field?	58 (87.9)	28 (71.8)	5 (7.6)	4 (10.3)	3 (4.5)	7 (17.9)

About 55% of patients and 81.9% of parents responded that they would like to receive information from an experienced specialist on IBD and nutrition.

In the paired analysis this difference was statistically significant comparing the patient and mother response with a similar tendency for the father but at limit of the significance.

DISCUSSION

While some evidence exists in adult patients, this is the first study evaluating children's beliefs and habits compared to a control group, including the parental point of view.

Patients' beliefs may arise from misinterpretation of events (i.e., patients may attribute symptoms to food because of a coincidence of time when in fact the symptoms are due to an IBD flare) and not be supported with scientific evidences. The knowledge of these beliefs is fundament to prevent inadeguate behaviours.

In this study one-third of patients and their parents believe that diet has a significant role in the course of IBD and the most common belief is that the avoidance of certain "negative" foods, rather than consuming some "positive" foods, could benefit IBD. The concept of avoidance is shared by many of the diets suggested in the last years for the treatment of IBD, including exclusive or partial enteral nutrition (EEN) (10,11).

Similarly to previous reports (5,6), 15% of children and 30% of parents believe that milk and dairy have a negative effect on IBD and a reduced intake of milk was observed compared to controls. We are not able to say if this belief concerned all types of milk or only milk containing lactose.

A higher prevalence of lactose intolerance has been reported in patients with IBD than the general population (12–14). However, fat but not lactose content on dairy products have been reported to influence symptoms on CD patients (15) and a dairy-free diet has shown no benefit on children and adults with UC (16,17).

While most of the diets commonly proposed to people with IBD suggest avoiding lactose-containing dairy or dairy at all (18), the Dietary Guidance from the IOIBD does not suggest limiting the consumption of milk and dairy except for the avoidance of unpasteurized milk due to the potential risk of infections (5).

Fatty, fried, and spicy foods, sweets and carbonated drinks are also considered harmful for the IBD course by both patients and parents. Some evidence exists on the excess of fats, particularly trans fats and certain saturated fats such as myristic acid, that can adversely affect UC and the cardiovascular system (5). While in previous cohorts, about 30-75% of children and adults with IBD reported avoiding fatty and spicy foods (6,8,19) in this study, their consumption was not different from healthy controls, probably because of their uncommon use in the Mediterranean diet style.

Currently, there is no evidence of the effect of refined sugars on intestinal inflammation. On the contrary, studies on animal models showed the proinflammatory effect of artificial sweeteners, emulsifiers, carrageenan or other additives to improve food texture, colour, coat, or preservation. However, studies on humans are lacking, and no apparent effect of these foods on IBD can be drawn (5).

Processed meats are not explicitly considered harmful foods by patients and families. Nonetheless, they can be included in the "fatty foods" category, and their daily consumption is reduced compared with healthy controls. Excessive consumption of red meat has been associated with a greater likelihood of UC development (4) and worsening of symptoms in patients with UC, and the IOIBD cautiously suggests reducing the intake. However, prospective trials showed that a diet low in red and processed meat does not reduce the flares for CD and UC patients (20,21).

TABLE 4. Foods believed to have a role in the course of IBD.

Foods believed to prevent a relapse or improve your symptoms in case of relapse			
	Children 75	Mothers 66	Fathers 39
Yes	25 (33.3)	30 (45.5)	16 (41.0)
No	25 (33.3)	15 (22.7)	10 (25.7)
Don't know	25 (33.3)	21 (31.8)	13 (33.3)
Vegetable/fruit	7 (28.0)	4 (13.3)	2 (12.5)
Rice	5 (20.0)	6 (20.0)	0
Pasta without any sauce	2 (8.0)	4 (13.3)	1 (6.2)
White meat	2 (8.0)	7 (23.3)	3 (18.8)
Potatoes	1 (4.0)	3 (10.0)	1 (6.2)
Bread	1 (4.0)	0	0
Dairy	1 (4.0)	4 (13.3)	0
Fish	1 (4.0)	2	2 (12.5)
Foods believed to promote a relapse or worsen your symptoms in case of relapse			
Yes	36 (48.0)	39 (59.1)	24 (61.5)
No	25 (33.3)	9 (13.6)	5 (12.8)
Don't know	14 (28.7)	18 (27.3)	10 (25.6)
Fat, fried and spicy food, sauces	12 (33.3)	12 (30.8)	8 (33.3)
Milk and dairy	5 (13.9)	11 (28.2)	8 (33.3)
Sweets	5 (13.9)	9 (23.1)	5 (20.8)
Sweet beverages	5 (13.9)	6 (15.4)	1 (4.2)
Legumes	5 (13.9)	8 (20.5)	1 (4.2)
Vegetable/fruit	4 (11.1)	9 (23.1)	7 (29.2)
Dried fruit	1 (2.8)	0	1 (4.2)
Fish	1 (2.8)	0	1 (4.2)
Gluten	0	4 (10.3)	1 (4.2)
Cured meat	0	1 (2.6)	0
Red meat	0	1 (2.6)	2 (8.3)
Eggs	0	1 (2.6)	0

Children attribute a positive effect to fruit and vegetables, perhaps because they have learned the general opinion that these are "healthy foods". Indeed, fibres are metabolized by colonic bacteria into short-chain fatty acids which have anti anti-inflammatory properties on intestinal cells (18). However, raw and cooked vegetables are consumed less frequently by patients than controls, possibly reflecting the concern expressed by parents of a worsening effect of fibre on intestinal symptoms. Actually, a low fibre diet is suggested only for patients with strictures, and this avoidance may be a maladaptive response to a general dietary recommendation (22).

Half of the patients and parents reported an influence of the IBD on the pleasure to eat, similarly to studies on adults (7). Elevated proinflammatory cytokines may induce loss of appetite and cachexia. However, in this study, patients' and parents' beliefs did not depend on the disease severity or phenotype. Some inconsistencies between beliefs and behaviours emerge in the study. In fact, more than half of the parents believe that there are foods that can promote an IBD relapse but only 40% report to have changed the diet proposed to their child. This could be explained by the lack of strength of parental belief or inability to implement lifestyle changes. Moreover, by answering "don't know" to questions about dietary beliefs, about 10-30% of patients and parents showed a lack of precise knowledge about diet. Remarkably, more than one-third reported obtaining diet-related guidance from sources other than their physician. Almost all parents expressed the desire to receive dietary advice from a specialist.

Acquiring dietary information from unreliable sources increases the risk of following selective diets. Inappropriate dietary patterns are the main risk factors for developing eating disorders such as anorexia nervosa or avoidant restrictive food intake disorder (ARFID), in which restrictive eating is motivated by concerns about the adverse consequences of foods (22). Young patients with IBD are particularly at risk for nutritional deficiencies, especially in situations of increased requirements due to malabsorption and increased nutrient losses and voluntary restrictive diets may promote malnutrition. Unnecessary avoidance of milk, for example, increases the risk of calcium and vitamin D deficiency and thus poor bone health (23). Moreover, restrictive diets may induce social limitation, worsen their quality of life and promote psychiatric comorbidities.

Except for the effects of fruits and vegetable, no significant differences were found for most of the responses given by children and parents, indicating that these beliefs are shared in the household.

Overall, these findings suggest a need for clear evidence-based messages for patients and their families from nutritionists and paediatric gastroenterologists treating IBD.

This study has some limitations. First, it was conducted on a limited number of patients through unvalidated questionnaires. Second, we cannot exclude that the previous patients' history and therapies, in particular exclusive enteral nutrition in patients with Crohn's disease, influenced the responses of patients and their parents. Third, the relationship between food beliefs, avoidance of certain foods, and clinical course of IBD over time and the impact of restrictive diets and nutritional status could not be assessed. This is a complex relationship in which individual variability and the changes that diet can induce on the intestinal microbiota and therefore on the inflammatory response come into play (24). Forth, it was not possible to enrol both parents for all the children, but, in most cases, the parent interviewed prepared the child's meals, thus making the interview responses reliable. Finally, in comparing dietary habits, controls were significantly younger than patients with IBD, even if still in adolescence.

CONCLUSIONS

The study showed that about one-third of paediatric patients with IBD and their parents have dietary beliefs and, in some cases, enact restrictive dietary behaviours.

Nutritional education and disease knowledge programs are actually desirable to avoid inappropriate and potentially harmful dietetic behaviours.

Future studies should investigate the complex interactions between food, microbiota and IBD and clarify which elements of the diet promote the development of IBD and play a role on its course in order to suggest correct and personalized eating habits.

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