

# Parental knowledge of chronic inflammatory bowel diseases in a child

## Znanje roditelja o kroničnim upalnim bolestima crijeva kod djeteta

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### Abstract

**Introduction:** Chronic inflammatory bowel disease is a chronic lifelong disease with various triggers, intermediate longer and shorter remissions. Parents need to know what kind of nutrition the child with chronic inflammatory bowel disease needs because they must be able to make the right decisions regarding the child's diet. The right choice of diet gives a child enough energy in their daily and enables the quality life. They must enjoy a healthy balanced diet so that they receive all the nutrients the body needs. In our work, we presented chronic inflammatory bowel disease in children and parents' assessment of the child's quality of life.

**Methods:** We chose a quantitative methodology to establish the impact of diet on the quality of life of the child with chronic inflammatory bowel disease. To describe and define the problem, we used a descriptive method. A structured measurement instrument was based on a review of the relevant foreign and domestic literature. Statistical data analysis was performed using descriptive and inferential statistics. Data were collected by a non-random and occasional sampling survey.

**Results:** We found that most children whose parents participated in this research have Crohn's disease (n = 20; 50%) and ulcerative colitis (n = 16; 40%). The type of food that is harmful to the child is fatty food (n = 33; 83%), followed by spicy food (n = 32; 80%) and acidic food (n = 10; 25%). According to the parents' assessment, children with chronic inflammatory bowel disease have good (n = 22; 55%) health. We found that physicians provide parents with the most necessary nutrition information. Through evaluation of the parents, we found that there is no statistically significant correlation between the general assessment of a child's health and the type of chronic inflammatory bowel disease ( $X^2(2) = 5.925, p = 0.052$ ). Also, there is no statistically significant correlation between the eating pattern and parents' assessment of their child's quality of life ( $U = 38.00, p = 1.00$ ).

**Discussion:** The health care providers have an important role to play in giving appropriate information to parents to ensure the quality of life of the child. She teaches parents and children about living with chronic inflammatory bowel disease and emphasizes the importance of nutrition, which greatly contributes to a better quality of life.

**Keywords:** Chronic illness, healthy diet, parents, health care providers, motivation

**Running head:** Chronically ill child

### Sažetak

**Uvod:** Kronična upalna bolest crijeva kronična je cjeloživotna bolest s raznim pokretačima te srednje dugim i kraćim remisijama. Izuzetno je važno da roditelju znaju kakva je prehrana potrebna djetetu kod kronične upalne bolesti crijeva jer moraju donositi ispravne odluke o djetetovoj uravnoteženoj prehrani. Pravilan odabir prehrane djetetu daje dovoljno energije u svakodnevnom životu i omogućava mu kvalitetan život. Djeca trebaju uživati u zdravoj uravnoteženoj prehrani kako bi dobivala sve hranjive sastojke koje tijelo treba. U radu je predstavljena kronična upalna bolest crijeva kod djece te procjena roditelja o kvaliteti djetetova života.

**Metode:** Za utvrđivanje utjecaja prehrane na kvalitetu života djeteta s kroničnom upalnom bolesti crijeva, odabrana je kvantitativna metodologija. Da bismo opisali i definirali problem, poslužili smo se opisnom metodom. Strukturirani mjerni instrument temelji se na pregledu relevantne strane i domaće literature. Statistička analiza podataka provedena je pomoću deskriptivne i inferencijalne statistike. Podaci su prikupljeni neslučajnim i povremenim istraživanjem uzorkovanja.

**Rezultati:** Rezultati pokazuju da djeca većine ispitanika imaju Crohnovu bolest (n = 20; 50%) i ulcerozni kolitis (n = 16; 40%). Vrsta hrane koja je štetna za dijete je masna hrana (n = 33, 83%), začinjena (n = 32, 80%) i kisela hrana (n = 10; 25%). Prema procjeni roditelja, djeca s kroničnom upalnom bolesti crijeva imaju dobro opće zdravlje (n = 22; 55%). Istraživanjem je pokazano da liječnici roditeljima pružaju najnužnije informacije o prehrani. Putem procjene roditelja rezultati pokazuju da ne postoji statistički značajna korelacija između opće procjene djetetova zdravlja i vrste kronične upalne bolesti crijeva ( $X^2(2) = 5,925, p = 0,052$ ). Također, ne postoji statistički značajna korelacija između načina prehrane i procjene roditelja o kvaliteti života njihova djeteta ( $U = 38,00, p = 1,00$ ).

**Rasprava:** Zdravstveni djelatnici imaju važnu ulogu u pružanju odgovarajućih informacija roditeljima kako bi se osigurala kvaliteta života njihova djeteta. Podučava roditelje i djecu o životu s kroničnim upalnim bolestima crijeva te ističe važnost prehrane koja uvelike doprinosi boljoj kvaliteti života.

**Ključne riječi:** Kronične bolesti, zdrava prehrana, roditelji, zdravstveni djelatnici, motivacija

**Kratak naslov:** Kronično bolesno dijete

## Introduction

Every illness, especially a chronic one, brings great changes in the child's life and the whole family [1]. Chronic diseases in children cause delays in developmental milestones in areas such as physical, language and communication, reasoning, social and emotional growth [2]. These delays affect the child, the family members, and the nation [3]. Chronic inflammatory bowel diseases (CIBD) are lifelong conditions that often begin in childhood [4]. They are immune-mediated disorders with a genetic component, characterized by chronic inflammation of the gastrointestinal tract [5] with a rising incidence in pediatric populations [6]. Epidemiological studies have demonstrated a rising incidence of CIBD in countries where the disease is more prevalent, such as Europe and North America and in other countries [7 - 9]. The number of Scottish children diagnosed with CIBD continues to rise, with a statistically significant increase of 76% since the mid-1990s [10]. The increasing trend in Finland is comparable with findings from several other countries (e.g., South Wales, Ontario Canada) [11]. The total annual average incidence of 7.6% per 100,000 children is present in northeastern Slovenia [12].

Chronic inflammatory bowel diseases, including ulcerative colitis and Crohn's disease, are chronic inflammatory disorders [6] that affect a child's quality of life. But, a high quality of life can also be ensured through appropriate medical treatment [13]. In the medical treatment of a child with chronic inflammatory bowel disease, it is extremely important to provide quality, comprehensive and safe nursing. The basic goal is to establish a partnership between the child, the parents, and the nurse [14]. Parents have a central role in the management of children with chronic inflammatory bowel disease [15]. Nutritional support is very important in the treatment of pediatric CIBD [16]. The diet of children with CIBD differs from the general pediatric population. Growth in children should be monitored regularly to ensure that food intake is not reduced and that the child nevertheless develops and grows normally [17, 18]. Nutrition is involved in several aspects of pediatric CIBD, ranging from disease etiology to induction and maintenance of disease [18].

### The importance of nutrition in a child with chronic inflammatory bowel disease

In children and adolescents with CIBD, controlling intestinal inflammation is an important aspect of treatment [17].

A functioning digestive tract is needed to extract nutrients from food. Most foods require digestion, as all nutrient substrates (proteins, carbohydrates, vitamins, minerals, fats, electrolytes) must be absorbed before further use [19]. It has been found that parents of children with CIBD do not follow any specific diet, but adhere to the principles of eating a healthy, proper, and protective diet [20]. The child's diet should be adjusted according to the symptoms of the disease (diarrhea, constipation, convulsions), the stage of the disease (active onset or remission), the location of the disease, previous operations, nutritional status, and nutritional deficit [20]. The child is advised to eat the food slowly and chew it well. Meals should be smaller and more

frequent. Food must be at a suitable temperature, not too cold and not too hot [21]. The nurse should advise the child's parents to cook or stew the food for the child. He advises avoiding fried, fatty, spicy foods, foods high in fibre and sweets [22]. Consumption of desserts, fatty foods and high-fibre foods also increases the exacerbation of the disease in children [23].

### The role of the nurse in the health care of a child with chronic inflammatory bowel disease

Nurses are available to families with children with CIBD twenty-four hours a day, seven days a week, during times of health and illness, and in all environments where families live, work, and spend their free time. Through their communication, they enable the establishment of trust and thus the possibility for the participation of children and their parents [24]. Its main task is health-educational work [25]. They teach the child and the parents until the child and the parents are authorized to receive CIBD and perform the activities correctly and independently. Well-educated children and their parents are more self-confident, live calmer lives, and take more correct and timely action when the disease relapses.

## Material and Methods

A cross-sectional survey was conducted among parents who have children with CIBD. We chose a quantitative methodology [26] to establish the knowledge of the parents about the CIBD and to find out parents' assessment of their child's quality of life. To describe and define the problem, we used a descriptive method. Professional and scientific literature was searched in databases (COBISS, Google Web of Science, PubMed) using inclusion (published between 2010 and 2020; full-text articles; professional and scientific articles in English) and exclusion criteria (published before 2010; non-full-text articles; professional and scientific articles in other languages). A structured measurement instrument was based on the review of the relevant foreign and domestic literature and the Nutrition Handbook for people with Crohn's Disease and Ulcerative Colitis [27]. The survey was composed of closed-ended questions. Statistical data analysis was performed by descriptive and inferential statistics. In confirming the hypotheses, we used the Kruskal Wallis test for the first and the Mann-Whitney U test for the second hypothesis. Statistical analysis of the data was performed with the computer program SPSS, version 17 and Microsoft Excel. The results are presented in graphic and tabular form.

### Research sample

Data were collected by a non-random and occasional sampling survey. In the survey, we invited parents of children with CIBD and forty parents agreed to the survey. 20 parents were interviewed at the Pediatric Clinic and the other 20 parents via the 1KA online survey.

### Research process and data analysis

At the beginning of the survey, we obtained approval from the Ethics committee of the organization. Before conduc-

ting the survey, we informed the parents about the purpose and goals of the survey and their rights and duties. We also informed them that participation in the survey is anonymous and voluntary and that they can withdraw from participation at any stage of the survey. The identity of the parents was not disclosed at any stage of the survey. We also considered declarations, documents and guidelines relating to the ethical aspect of the survey [28-32].

### Research questions and hypotheses

We set the following research question:

RV1: Who provides parents of children with chronic inflammatory bowel disease with the most necessary nutrition information?

We set the following hypotheses:

H1: There is a link between the general assessment of a child's health and the type of chronic inflammatory bowel disease.

H2: There is a link between the eating pattern and parents' assessment of their child's quality of life.

### Results

The majority of the participants in this study were mothers (n = 30; 75%), followed by fathers (n = 10; 25%).

Most children have had Crohn's disease (n = 20; 50%), followed by ulcerative colitis (n = 16; 40%). Intermediate (indeterminate) colitis occurred rarely (n = 4; 10%).

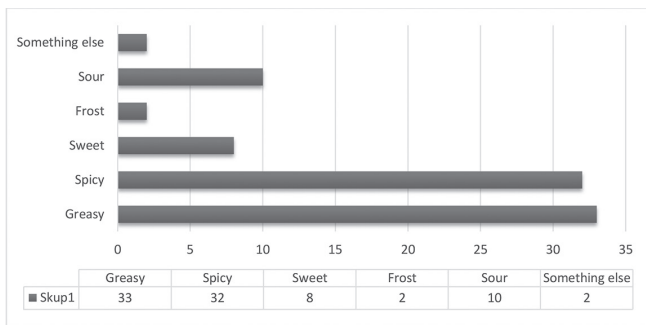


FIGURE [1] Knowledge of parents about harmful food

In Figure 1 we present parents' knowledge about the food that harms a child with CIBD and consequently influencing the quality of the child's life. In the first place, parents listed fatty food (n = 33; 83%), followed by spicy food (n = 32; 80%) and acidic food (n = 10; 25%). Food that harms a child with CIBD is also sweet food (n = 8; 20%) and salty food (n = 2; 5%). In the second option, parents listed dairy products (n = 2; 5%).

Figure 2 shows the parental subjective assessment of health and quality of life of a child with chronic inflammatory bowel disease. According to the parents' assessment, children with CIBD have well (n = 22; 55%) overall health.

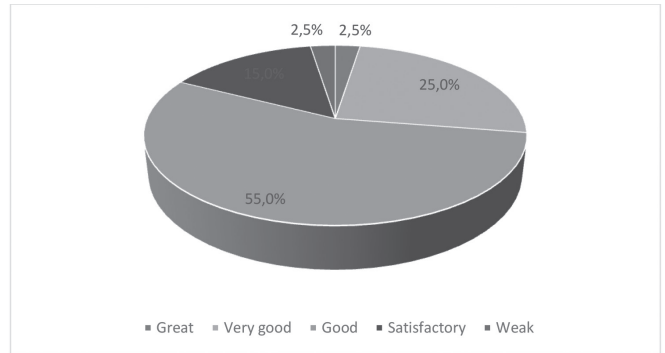


FIGURE [2] The parental general assessment of the child's health

Other parents assessed their child's health as very good health (n = 10; 25%). The third most marked answer is satisfactorily assessed child's health (n = 6; 15%), excellent (n = 1; 2.5%) and poor (n = 1; 2.5%), both of which were answered once by the respondents.

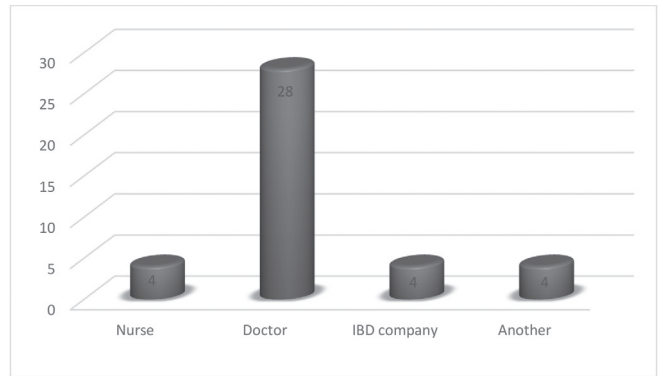


FIGURE [3] Teaching and informing parents about child's diets

Physicians (n = 28; 70%) provide parents with the most necessary nutrition information. Nurses (n = 4; 10%), the IBD companies (n = 4; 10%) and information from the Internet (n = 4; 10%) share a second place and also contribute to the necessary information regarding the nutrition of children with CIBD.

Figure 4 shows how parents assess the information they receive from nurses. Respondents who believe the information they receive is sufficient answered "yes" and that was the most common answer (n = 25; 63%). The answer "no"

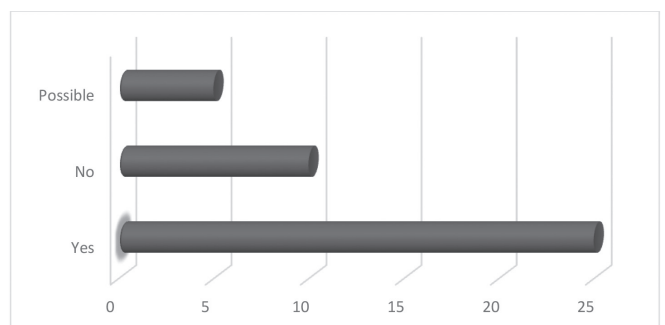


FIGURE [4] Obtaining sufficient information from nurses

appeared 10 times (25%). The least selected answer was "possible" ( $n = 5$ ; 13%). This question was set because we were interested in parents' perception of the nurse's role in providing health information.

In proving the hypotheses, we used the Kruskal Wallis test to refute the first hypothesis ( $X^2(2) = 5.925$ ,  $p = 0.052$ ). This means that we did not prove the link between the general parental assessment of a child's health and the type of chronic inflammatory bowel disease. The child's general health was assessed by their parents. Using the Mann-Whitney U test, we refuted the second hypothesis ( $U = 38.00$ ,  $p = 1.00$ ). There is no statistical significance to prove that there is a link between the eating pattern and parents' assessment of their child's quality of life. Parents have circled how many meals the child has per day. Possible answers were 2 or less, 3 – 5, or more than 5. We found that there was no link between the number of meals and the quality of a child's life.

## Discussion

The research aimed to find out the parent's assessment about their knowledge about CIBD among children and to find out how parents assess the quality of life of children with CIBD. The parents' right choices about diet give a child enough energy in their daily and enable a quality life. The survey involved 40 parents of children with CIBD, of whom three-quarters were mothers and a quarter were fathers. We also established who provides the parents with the most information regarding the diet of a child with CIBD. We found that 70% of the surveyed parents are provided with information on child diet by physicians. Although parents did not choose nurses as the most important persons in delivering important information to parents, nurses have an educational role. There is an opportunity to promote the nurse's role to ensure better parents' knowledge and satisfaction with the health care system. Other authors emphasize the role of nurses in a discussion about the course of the disease, its symptoms, possible complications, treatments, dietary treatment and lifestyle changes for a better quality of life for a chronically ill child [33].

In the final part, we also set two hypotheses. The first hypothesis is whether there is a link between the general assessment of a child's health and the type of CIBD. Using parental assessment, we found out that there is no association between the overall assessment of a child's health and the type of CIBD. Parents also estimated in the survey that more than half of the children are in good health and live a quality life. Every child with CIBD has several factors that intertwine and influence the course of the disease and consequently the overall assessment of the child's health (eating and drinking, movement of the child, quality sleep, emotional development of the child, environmental factors, etc.) [34]. Parents of children with Crohn's disease and ulcerative colitis consider the quality of life to be the standard and community of family life [35].

The second hypothesis predicted that there is a link between the eating pattern and parents' assessment of their child's quality of life. We also refuted the second hypoth-

esis because there is no difference in the quality of life between those who eat 3 – 5 meals a day and those who eat more than 5 meals a day. Our research shows that almost all parents are satisfied by the quality of life of their children with CIBD. There are few parents (10%) who believe that their child could have a better quality of life. Mutual trust between the child, parents and health care professionals is crucial to ensure compliance with the diet required by CIBD, which contributes to a better quality of life [36]. The eating pattern is different for each child. We were interested in food that triggers illness in a child. The most common responses were fatty food (83%) and spicy food (80%).

## Conclusion

Childhood is a vulnerable period of development in which there are significant differences in nutritional needs. During health care, health care workers should have appropriate and evidence-based knowledge to provide parents and children with needed information about disease. Moreover, health care workers should perform competent health education. As evident, physicians are providing the most information about CIBD and diet to parents and children. Thus, future research should focus on nurse's education about CIBD among children and health education of parents with children with CIBD. Parents must choose the right diet because choosing proper diet gives a child enough energy in their daily and enables him a quality life. We found that there is no dietary pattern to heal the disease, but some types of foods, such as fatty and spicy food, greatly exacerbate the course of a child's disease. With this, we also proved that food has an important role in CIBD because the child is the one who will know which food suits him best and which not.

## Conflict of interest

**Authors declare no conflict of interest.**

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