

ASSESSMENT OF THE LEVEL OF KNOWLEDGE ON INFLAMMATORY BOWEL DISEASE IN PARENTS OF CHILDREN HOSPITALIZED IN THE CHILDREN'S MEMORIAL HEALTH INSTITUTE (IP-CZD)

OCENA POZIOMU WIEDZY NA TEMAT NIESWOISTYCH ZAPALEŃ JELIT W GRUPIE RODZICÓW DZIECI HOSPITALIZOWANYCH W CENTRUM ZDROWIA DZIECKA

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ABSTRACT

Introduction. Inflammatory bowel disease (IBD) is a group of autoimmune conditions that include Crohn's disease and ulcerative colitis. Due to an immunocompromised state, parents should have a high level of knowledge of available vaccinations, various therapies as well as possible complications that may develop in their children.

Aim. Assessment of knowledge on inflammatory bowel disease in parents of children hospitalized in the Children's Memorial Health Institute (IP-CZD)

Material and Methods. 45 parents of children hospitalized in the Department of Gastroenterology, Hepatology and Nutrition, Children's Memorial Health Institute (IP-CZD) between April and June 2015 (28 women); mean age: 43 years. An anonymous, voluntary survey: a questionnaire comprised 25 questions. Statistical analysis: STATISTICA 10.0, significance level at $p < 0.005$.

Results. Less than half of the respondents knew that osteoporosis was a recognised complication of inflammatory bowel disease. Over half of the respondents did not know that complications of IBD included also recurrent respiratory infections and that children with inflammatory bowel disease should avoid eating raw meat and eggs.

Conclusions. General knowledge of the disease among respondents was insufficient. It would be advisable to develop an educational campaign, introduce a larger number of consultations with dietitians and improve methods of communication.

KEYWORDS: bowel disease, Crohn's disease, ulcerative colitis.

STRESZCZENIE

Wstęp. Nieswoiste choroby zapalne jelit (NZJ) to choroby autoimmunologiczne, do których zalicza się chorobę Leśniowskiego-Crohna oraz wrzodziejące zapalenie jelita grubego. Ze względu na stan obniżonej odporności rodzice powinni posiadać wysoki poziom wiedzy na temat możliwych szczepień, stosowania różnorodnego leczenia, jak i na temat ewentualnych powikłań choroby, jakie mogą dotknąć dziecko.

Cel. Ocena wiedzy rodziców dzieci hospitalizowanych w Instytucie „Pomnik – Centrum Zdrowia Dziecka” na temat nieswoistych zapaleń jelit.

Materiał i metody. 45 rodziców hospitalizowanych dzieci w Klinice Gastroenterologii, Hepatologii i Żywienia Instytutu „Pomnik – Centrum Zdrowia Dziecka” w okresie od kwietnia do czerwca 2015 r. (28 kobiet); średni wiek 43 lata. Anonimowe, dobrowolne badania ankietowe: kwestionariusz składający się z 25 pytań. Analiza statystyczna: STATISTICA 10.0, poziom istotności $p < 0,005$.

Wyniki. Mniej niż połowa ankietowanych wiedziała, że do powikłań nieswoistych chorób zapalnych jelit należy osteoporoza. Ponad połowa respondentów nie wiedziała, że do powikłań zaliczają się również nawracające zakażenia układu oraz że dziecko chorujące na nieswoiste zapalenie jelit powinno unikać spożywania surowego mięsa oraz jajek.

Wnioski. Ogólna wiedza ankietowanych w badanej grupie na temat choroby jest niewystarczająca, należałoby rozważyć zastosowanie programu edukacyjnego, większej liczby konsultacji dietetycznych czy też wdrożyć lepsze sposoby przekazywania informacji.

SŁOWA KLUCZOWE: choroby jelit, choroba Leśniowskiego-Crohna, wrzodziejące zapalenie jelita grubego.

Introduction

Inflammatory bowel disease (IBD) is a group of autoimmune conditions that include Crohn's disease and ulcerative colitis [1]. In approximately 25% of all cases, the first manifestations of these diseases occur in persons below 20 years of age [2]. Apart from those two major and most common conditions, inflammatory bowel disease comprises also a number of similar conditions that need to be differentiated due to the further treatment and clinical picture [3].

Inflammatory bowel disease is believed to be caused by genetic, immunological, and environmental factors [4]. Psychological factors and nutrition patterns cannot be forgotten, though [2].

The aim of treatment of inflammatory bowel disease is to achieve remission and not complete recovery due to the chronic nature of the disease. Patients with IBD should be under constant care of a gastroenterologist, dietician and psychologist as well. In the case of children, it is of particular importance that their parents had a high level of knowledge and awareness of the disease, including knowledge of aetiology and causes of the disease as well as, first and foremost, dietary and nutritional recommendations, pharmacology, and the child's lifestyle [2].

Due to an immunocompromised state, parents should have a high level of knowledge of available vaccinations, various therapies as well as possible complications that may develop in their children [2].

Aim

The study aimed to assess the knowledge of parents of children hospitalized in the Children's Memorial Health Institute (IP-CZD) about inflammatory bowel disease. The detailed aim of the study was to compare the level of knowledge of inflammatory bowel disease among two groups: parents of children receiving biological therapy and parents of children treated with other methods.

Material

The study enrolled a total of 45 parents of children hospitalised in the Department of Gastroenterology, Hepatology and Nutrition, Children's Memorial Health Institute due to inflammatory bowel disease (children's mean age 14,5 years, min. 9, max. 17, SD = 2,24). In 100% of children the disease was diagnosed at least one year before the survey was conducted (date of diagnosis: 1999–2013). The study participants were divided into two groups: those whose children were receiving biological therapy (30 persons) and parents of children not receiving biological therapy (15 persons).

Mean age of the respondents was 43 years, the youngest person was 34 and the oldest one was 53. The study group comprised 28 women (62%) and 17 men (38%). The largest number of parents of children not receiving biological therapy had a secondary school degree (67%) and the largest proportion of those whose children were treated with Infliximab had a higher level degree (60%). The difference in the educational level between the groups was statistically significant and amounted to $p < 0.0145$.

Methods

The study was performed between April and June 2015 in the Department of Gastroenterology, Hepatology and Nutrition, Children's Memorial Health Institute in Warsaw. A diagnostic survey carried out with the use of a questionnaire was used in the study. Participation in the study was voluntary. The anonymous questionnaire comprised 25 questions about inflammatory bowel disease, including 4 questions concerning attitudes and opinions towards the participants' own level of knowledge. The data were collected in the Microsoft Excel program. The statistical analysis of the results was conducted using STATISTICA 10.0. program (licensed to Warsaw Medical University). Two groups were compared in the study: parents of children receiving biological therapy and parents of children not receiving biological therapy. The significance level was established at $p < 0.005$.

Results

The study demonstrated that parents of children with inflammatory bowel disease do not have sufficient knowledge of the factors affecting the development of the disease. Answers provided by both groups did not differ significantly except for a question about genetic factors ($p < 0.0083$) and a question about past vaccinations and their influence on the development of the disease ($p < 0.0016$). Parents of children receiving biological therapy demonstrated a better knowledge in the case of both questions.

The respondents demonstrated a high level of knowledge with respect to the question about the symptoms of inflammatory bowel disease. Statistically significant differences concerned answers to questions about the elevated body temperature ($p < 0.038$), perianal lesions ($p < 0.0001$), and nausea and vomiting ($p < 0.0102$). Parents of children receiving biological therapy had a better knowledge concerning the issues above.

Less than half of the respondents knew that osteoporosis is a recognised complication of inflammatory bowel disease. Over half of the study participants did not know that complications also include recurrent

respiratory infections. There were no significant differences between the answers provided by both groups except for the questions about joint pain and oedema ($p < 0.0012$) as well as ocular complications ($p < 0.0441$). In both cases, parents of children receiving biological therapy demonstrated better knowledge.

See **Table 1** for a detailed comparison of results in both groups.

Table 1. Symptoms and signs of inflammatory bowel disease and factors affecting its formation and progress

	Patients treated with infliximab			Patients not treated with infliximab		
	Yes	No	I don't know	Yes	No	I don't know
Contribution of genetic factors to the development of the disease	66.6%	6.7%	26.7%	21.4%	35.7%	42.9%
Contribution of past vaccination to the development of the disease	3.6%	78.6%	17.8%	21.4%	21.4%	57.2%
Elevated body temperature as a sign of the disease	55.2%	24.1%	20.7%	14.3%	50%	35.7%
Perianal lesions as a sign of the disease	79.3%	13.8%	6.9%	20%	13.3%	66.7%
Nausea and vomiting as a sign of the disease	69%	17.2%	13.8%	28.6%	14.3%	57.1%
Joint swelling as a possible complication of IBD	83.3%	6.7%	10%	28.6%	14.3%	57.1%
Symptoms of/eye disease as a possible complication of IBD	41.4%	34.5%	24.1%	30.8%	7.7%	61.5%

Source: author's own analysis

Nearly three quarters of the respondents gave a correct answer that parents could not (without consulting a doctor) decide to discontinue steroid treatment of their children. Over half of the parents knew that in the case of overweight in a child on steroid therapy they were not supposed to change any instructions provided by a dietitian and attending doctor. More than half of the study participants had knowledge about the contribution of the Polish National Health Fund (NFZ) towards financing the biological therapy. The answers provided by both groups did not differ significantly.

More than 50% of the respondents had knowledge about physical activity of a child with inflammatory bowel disease. Over half of the study participants did not know whether their child could be vaccinated.

Only half of the study participants knew that a child with inflammatory bowel disease should avoid eating raw meat and eggs. Over 50% of the parents knew that their children absolutely could not drink Coca-Cola. The

answers provided by both groups did not differ significantly.

The question about consumption of milk by a child with inflammatory bowel disease proved to be statistically significant. Over half of the parents responded correctly that their children could drink milk. The parents of children receiving biological therapy demonstrated a higher level of knowledge with respect to this question.

Over half of the respondents did not provide the correct answer to the question about elimination diets. The parents did not know that such a diet may lead to nutritional deficiencies. Two thirds of the respondents did not know that deficiency of trace elements such as magnesium or potassium might aggravate diarrhoea in their child. The answers provided by both groups did not differ significantly.

Over half of the respondents did not know that in the case of fatty diarrhoea it was recommended to limit fat intake. Differences between answers provided by both groups were statistically significant ($p < 0.0126$). More correct answers were provided by the parents of children receiving biological therapy.

See **Table 2** for statistically significant differences in detail.

Table 2. Detailed knowledge of nutrition principles for children with IBD

	Patients treated with infliximab			Patients not treated with infliximab		
	Truth	False	I don't know	Truth	False	I don't know
Consumption of milk	16.7%	70%	19.3%	6.4%	33.6%	60%
Children's fat intake	26.7%	13.3%	60%	6.7%	53.3%	40%

Source: author's own analysis

Nearly half of the respondents did not know that the consumption of juice and fruit purée irritated the inflamed intestines.

The next questions concerned Infliximab, a biologic drug. Over three-fourths of the study participants knew the group of medicines Infliximab belonged to. Statistically significant differences ($p < 0.001$) in favour of the parents of children receiving biological therapy were observed with respect to the question about the route of administration of a biological drug.

Most parents provided correct answers to the open-ended questions about the biological drug infusion time and the post-infusion clinical observation period. The drug infusion normally takes about 2–3 hrs. and the post-infusion observation of a child should last a minimum of 2 hrs.

The parents had major difficulties with the question about adverse effects of the biological drug. Most respondents were not able to indicate possible reactions after taking Infliximab. There were no statistical differences between the groups except for the question about breathing difficulties ($p < 0.0369$).

Less than half of the study participants assessed their knowledge of the child's disease as good. The Internet and a doctor constituted the main sources of knowledge of the study population about the disease. The answers provided by both groups did not differ significantly. Over half of the respondents did not provide any area of knowledge about their children's disease they would have liked to improve. No statistically significant differences in answers between the groups were found except for the question concerning the willingness to improve knowledge with respect to complications of the disease ($p < 0.0042$), with parents of children receiving biological therapy being more interested in improving their knowledge about complications.

Discussion

Not many publications on the assessment of parents' knowledge on inflammatory bowel diseases were found in the available Polish literature included in the Polish Medical Bibliography. The available publications have focused mainly on the evaluation of life quality of children and adolescents with inflammatory bowel disease [5, 6, 7, 8, 9, 10].

The world literature included in the PubMed and Scopus databases provides a larger number of publications as well as tools to measure the level of knowledge. The Knowledge Questionnaire, i.e. a questionnaire assessing the knowledge of adults with inflammatory bowel disease was developed by S.C. Jones in 1992 [11]. A study based on this questionnaire demonstrated certain mistakes in understanding the disease by patients, however a large proportion of patients wanted to have a better knowledge of inflammatory bowel disease. Similar results were obtained in the present study: the respondents expressed their willingness to improve their knowledge of nutrition, medication therapy, and new possibilities of treatment available to paediatric patients.

The CCKNOW score developed in 1999 by J.A. Eaden constitutes another research tool [12]. The Crohn's and Colitis Knowledge Score is a 24-item questionnaire assessing the knowledge of adult patients with Crohn's disease and ulcerative colitis. The questions were divided into five areas: 8 questions related to general knowledge, 4 human anatomy-related questions, 5 questions about drugs, 2 nutrition-related questions and 5 questions concerning complications. The study conducted in NHS facilities in eight regions of the UK demonstrated

a low level of knowledge of patients with IBD about the disease – median score on the CCKNOW was 9. At the same time, the respondents (127 study participants) did not assess their knowledge as poor [13]. These results correspond to the present outcomes, where parents of young patients with inflammatory bowel disease also presented a low level of knowledge, with a relatively good self-assessment.

A study carried out in Manchester among a group of 236 patients with IBD [14] is another one assessing the level of knowledge with the use of the CCKNOW questionnaire. In this case the score was only 7. The results of this study and the outcomes of the previous one of 1999 were similar, giving the mean score of 10 [12]. Both the original study and the one conducted in Manchester showed a poor level of knowledge with respect to fertility, surgical procedures and implications for pregnancy. The scope of questions in the present study concerned other areas of the disease, still, the level of knowledge was low. The highest score was achieved by patients in Canada, amounting to 13, and the lowest one was obtained in Iran, with the mean of 4 [15, 16].

Large differences between Western European countries and developing countries (Iran) can be attributed to the quality of health care, limited access to websites, and a small number of publications. Nevertheless, debates and discussions on the usefulness of the CCKNOW questionnaire are on-going. Patients from hospital in Tehran (100 persons) had the lowest level of knowledge about the complications of bowel diseases. The present study participants also had difficulties in defining possible complications. Another similarity between the two studies concerns the willingness to improve knowledge of available treatment options. However, none of the aforementioned questionnaires (Knowledge Questionnaire and CCKNOW) could have been used to assess knowledge of children and adolescents. It was possible only thanks to a study by D. Haaland, A.S. Day and A. Otley that demonstrated a IBD-KID device (Knowledge Inventory Device), a questionnaire assessing the knowledge of children aged between 10 and 17 [17]. It is filled in by both parents and children. The assessment of and studies on the questionnaire showed that it was an important and efficient measurement tool. It was tested for validity among 99 parent-child pairs. Similarly to the present findings, the first results showed that more than half of the parents and less than half of the patients had not noticed complications of the disease in a part of the body other than the intestines. As with the present study, less than half of the respondents did not indicate osteoporosis and eye diseases as complications of the disease. Less than half of the parents and more than half of the patients had knowledge about the adequate

diet and above all its relation to health of a child. This corresponds with the present study results that showed that the parents of children with IBD did not have a high level of knowledge on nutrition and dietetics.

The IBD-KID questionnaire was also useful and valid in an Australian study whose results demonstrated poor knowledge of a wide variety of treatment aspects of IBD as well as its complications, which was, again, in line with the present outcomes [18]. Major medical organisations in the UK developed common guidelines and standards providing IBD patients with the highest quality care and emphasising the importance of the level of knowledge of patients for the course of the disease [19]. Another interesting analysis was carried out among gastroenterologists who were asked to assess the knowledge of adolescents reaching adulthood. It showed poor knowledge of young adults: more than 50% of the study participants had deficits in the knowledge of their case history and drug-intake schedule [20].

There are just a few Polish publications on inflammatory bowel disease devoted to the knowledge of parents or children and adolescents with enteritis. A publication by M. Perek and G. Cepuch is one of them [7]. The study enrolled both young patients and their parents. According to the authors, the study participants had a satisfactory knowledge of inflammatory bowel disease. Only 9% of respondents indicated genetic factors as the cause of the disease, whereas the genetic load was indicated by as many as 52% of the present study participants. The question about symptoms in the study by M. Perek and G. Cepuch as well as in the present study showed a high level of knowledge: in both studies the respondents listed abdominal pain, diarrhoea, weight loss, nausea and vomiting. In both studies, medical personnel (31% in a study by M. Perek and as many as 7% in the present study) and the Internet (45% and 75%, respectively) constituted the main sources of knowledge of patients and their parents about the disease.

The present study, similarly to the others mentioned above, demonstrated poor knowledge of inflammatory bowel disease. The results obtained by M. Perek, who assessed the knowledge as satisfactory, may be referred to the present outcomes only in a few aspects. It can be assumed that the knowledge of parents in the present study about the symptoms of the disease resulted from their own experience since the percentage of correct answers to the questions about dietary recommendations was insufficient (poor knowledge with respect to consumption of raw food products, milk, Coca-Cola, as well as elimination diets and diarrhoea caused by certain deficiencies). The knowledge of safety and vaccination was also unsatisfactory. Over two-thirds of the respondents were unable to indicate

whether they could get vaccinated with particular vaccines available on the market.

The general level of knowledge of parents and children receiving biological therapy about the infusion route and what to do if a dose is missed was sufficient, however the lack of knowledge of post-infusion adverse effects and when they can occur raises concerns. No similar publications or studies were found in the Polish and world literature. The percentage of correct answers regarding possible complications was between 4 and 29%. Not a single study participant indicated the correct period when complications were most likely to occur (up to two weeks post infusion). In spite of that, as many as 74% of the respondents correctly indicated the procedure to follow if a dose of a biological medicine was missed and as many as 100% of the study participants showed up for a scheduled consultation with a gastroenterologist.

Conclusions

1. General knowledge of the disease among respondents was insufficient. It would be advisable to develop an educational campaign, introduce a larger number of consultations with dieticians and improve methods of communication.
2. The parents of children receiving biological therapy had better knowledge of symptoms, complications, and dietary recommendations, however, these were not significant differences. They need to be provided with a better access to information on biological therapy.
3. The comparison of the present results and the available Polish and world studies showed similar outcomes: the knowledge of the disease and its complications was insufficient.
4. The analysis of the available literature demonstrated that more research tools are needed and there is a need for more analyses of knowledge of adolescents and parents of children suffering from inflammatory bowel disease.
5. Doctor-patient communication and nurse-patient communication should be improved to decrease the role of the Internet in gaining information.

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