

The knowledge and expectations about IBD – difference between pediatric patients and their parents

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Abstract

Background and study aims : The aim of this prospective survey was to determine and compare the knowledge of children with inflammatory bowel disease (IBD) and their parents about their disease. Furthermore, patients and parents were asked to provide the main source for disease related information and to give opinion for possible improvement.

Patients and methods : This was a prospective survey which included children with IBD with ≥ 12 years of age and their parents. Only ambulatory patients treated in tertiary medical center were included.

Results : 38 child/parent pairs (79% mothers) were enrolled. Major differences between parents and children were in a) internet search where majority of parents ($n = 28$; 73.7%) and only 17 (44.7%) children gathered disease related information over the internet ($p = 0.01$) ; b) need for participation in patients' organization (97.4% parents comparing 55.3% children would like to participate ; $p < 0.001$) and c) clinical practice with time reserved for child/adolescent to be with his/her physician alone (78.9% of parents encourage this practice comparing to 2.6% of children ; $p < 0.001$).

Conclusion : This study shows significant difference between children/adolescents with IBD and their parents in several aspects that should be acknowledged before initiating changes into the clinical practice. (*Acta gastroenterol. belg.*, 2017, 80, 279-282).

Key words : inflammatory bowel disease ; internet search ; patients' organization

Introduction

Inflammatory bowel disease (IBD) has a significant emotional, psychological and social impact on the child's or adolescent's life. Impairments in the quality of life (QoL) have been clearly shown in several studies undertaken in different countries (1, 2). Therefore, children and their parents often seek help not only from health professionals but also through patients' organizations. Moreover, inadequate knowledge on various aspects of the disease (symptoms, medication side effects, prognosis...) has been repeatedly identified as the major obstacle for a successful transition to adult health providers (3). However, data in the literature regarding the knowledge, self-awareness and source of information for children/adolescents and their parents is lacking.

With the aim to improve healthcare and the organization of clinical practice for pediatric IBD patients we decided to determine and compare the knowledge of children with IBD and their parents about their disease, the source

where they obtain disease related information, and how this could be improved.

Methods

This was a prospective study which included children with IBD with ≥ 12 years of age and their parents. From January 2016 until May 2016 all children/adolescents with IBD and their parents who presented at the outpatient clinic were asked to participate in the survey. All children at the time of survey were in clinical remission assessed by their clinician. Children and their parents filled-in the survey on the separate tables in order not to compare answers between themselves. Questionnaire had 10 questions

(Tables 1 and 2), with few questions being the same in both groups (Table 3). Only after the study was completed.

Primary outcome was to see how children and their parents are satisfied with their knowledge about the disease and whether there is a difference between these two groups.

Secondary outcomes were to determine the major sources of information on the disease itself, and whether participation in the patients organization and changes in clinical practice would be considered beneficial, with a special emphasis on providing separate time for the communication of the child/adolescent his/her physician alone (without parents/caretakers).

Statistics. The differences between categorical variables were assessed by chi-square test. P-values of < 0.05 have been considered as statistically significant. Statistical analysis was performed using SPSS 19.0 (Chicago, IL) statistical software.

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Table 1. — Questions asked only to parents.

Question	N (%)
If you look for the information over the internet, what is important for you:	
a) It is important who is giving the information	10 (26.3)
b) I read all available data	12 (31.6)
c) I believe only the web pages written or edited by physicians	13 (34.2)
d) I ask other parents for specific web pages	1 (2.6)
e) Other	0
I think that my child has good knowledge about his/her disease:	
a) Yes	29 (76.3)
b) No	9 (26.7)
I think that I am the best source of information for my child:	
a) Yes	15 (39.5)
b) No	23 (60.5)
I would like that there is a patient organization for children with IBD	
a) Yes	37 (97.4)
b) No	1 (2.6)

Table 2. — Questions asked only to patients.

Question	N (%)
I would like to meet my peers who suffer from the same disease:	
a) Yes	26 (68.4)
b) No	12 (31.6)
I would like to have opportunity to communicate with other pediatric IBD patients over Facebook, Twitter...	
a) Yes	17 (44.7)
b) No	21 (55.3)
I would like that there are some web pages where I can ask questions and get answers anonymously:	
a) Yes	17 (44.7)
b) No	21 (55.3)

Table 3. — Differences in the answers to the questions shared between parents and their children.

Question	Parents	Patients	p
In my opinion my knowledge about the disease is:	N (%)	N (%)	p
a) Very well	4 (10.5)	2 (5.3)	0.395
b) Adequate	28 (73.7)	32 (84.2)	0.26
c) Poor	5 (13.2)	3 (7.9)	0.455
d) Insufficient	1 (2.6)	1 (2.6)	1.0
Information about the disease I have received mostly from: (multiple answers are allowed)	N (%)	N (%)	p
a) Gastroenterologist who is treating me/my child	38 (100)	28 (73.7)	
b) From the patient leaflet	4 (10.5)	1 (2.6)	0.165
c) From other patients/parents	2 (5.3)	10 (26.3)	0.012
d) On the Internet	10 (26.3)	6 (15.8)	0.260
e) Other _____	0	0	
Do you look for the information about the disease on the Internet?	N (%)	N (%)	
a) Yes	28 (73.7)	17 (44.7)	0.01
b) No	10 (26.3)	21 (55.3)	
I think my child can ask me anything regarding his/her health and disease / I can ask my parents anything related to my health and disease	N (%)	N (%)	p
a) Yes	38 (100)	36 (94.7)	0.152
b) No	0	2 (5.3)	
I think that my child should have opportunity to ask physician about any problem without my presence/I would like to have an opportunity to ask my physician some questions without my parents being present	N (%)	N (%)	p
a) Yes	30 (78.9)	1 (2.6)	<0.001
b) No	8 (21.1)	37 (97.4)	
If there would be a patients' organization I would certainly participate	N (%)	N (%)	p
a) Yes	37 (97.4)	21 (55.3)	<0.001
b) No	1 (2.6)	17 (44.7)	

Results

There were altogether 38 child/parent pairs included in the study. Mean age was 14.6 years (range 12-18.1 years), 18 girls and 20 boys. Majority of parents (79%) were mothers. Answers to questions asked only to parents are presented in a Table 1 and only to children in Table 2.

Majority of patients and their parents think that they have adequate knowledge about their disease (Table 3). Other secondary outcomes are presented in Table 3. Major difference between patients and their parents is in the rate of internet search ; significantly higher proportion of parents search information over the internet comparing to their children (73.7% vs 44.7%, $p = 0.01$). Furthermore, higher proportion of parents would like to be included in the patients' organization (97.4% vs 55.3%, $p < 0.001$). Parents also support the clinical practice where child/adolescent would have some time alone with his/her physician significantly more often than children (78.9% vs 2.6%, $p < 0.001$) (Table 3).

Discussion

Best to our knowledge, this is the first study which compared an awareness and attitude towards disease related information in children with IBD and their parents. This survey shows that pediatric patients with IBD and their parents rank their knowledge about the disease as adequate, and although the main source of information for both groups was their treating physician this was more pronounced in parents than in children. Furthermore, children tend to collect information from other patients significantly more often than parents.

There are no studies designed to see difference between children and their parents in the self-awareness regarding the knowledge about the disease and source of information. There are, however, studies which aimed to investigate difference in the QoL perception between pediatric IBD patients and their parents (6)(7). These studies, as well as studies in children with other chronic disease, did not yield uniform results

children to spend some time alone with their physician, on contrary, only minority of children (2.6%). Other major finding is the difference in the attitude towards formation and participation in patients' organizations. In this study almost all parents were in favor for patients' organizations compared to only 55% of children. There are several possible explanations for this, mainly related to the pubertal and adolescent age of included patients when they are less likely to share their emotions with

their peers. Furthermore, different information could have been obtained if they have already experienced participation in the patients' group. Nevertheless, it seems that these organizations should be oriented towards parents providing the room for children only if they are willing to join.

Limitations of this study include the use of survey and not validated questionnaire which would eliminate possible confounding factors. However, strengths include unique insight into the needs of children/adolescents with IBD and their parents, prospective design meaning that all children who were presented at the outpatient clinic of our hospital were included minimizing selection bias. Furthermore, children and parents filled in the survey separately without looking at each other answers.

In conclusion, this study shows specific differences in the attitudes between the children with IBD and their parents, particularly in respect to the sources of information, participation in the patients' organization and in respect to the communication with the treating physicians.

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