

ORIGINAL PAPER

The use of complementary and alternative medicine in Polish children with inflammatory bowel disease: single-centre survey-based study

Katarzyna Gerkowicz, Barbara Kołakowska, Monika Pawlak, Marcin Dziekiewicz

Department of Paediatric Gastroenterology and Nutrition, Medical University of Warsaw, Warsaw, Poland

ABSTRACT

Introduction: The paediatric population represents a substantial group of patients suffering from inflammatory bowel disease (IBD). Because IBD is a chronic condition, children and their parents are more willing to try complementary and alternative medicines (CAM). There has been no study on this subject in Poland. The aim of our study was to investigate the usage of CAM in children with IBD and parental attitudes towards them.

Material and methods: An anonymous survey was conducted among parents of children suffering from IBD. The questionnaire included socio-demographic data, medical history of the child, as well as the parental opinion on their knowledge and attitude towards CAM.

Results: Thirty-seven surveys were filled in. The mean patient and parent ages were, respectively, 14.0 ±3.2 years (range 5.4–17.9) and 40.2.2 ±5.1 years (range 25–49). The mean disease duration was 3.7 ±2.4 years. CAM was used in 32.4% of patients at any time. The most frequently used CAM treatments were fermented food (10.8%), linseed (10.8%), and a lactose-free diet (8.1%). 25% of CAM users declared a decrease in symptoms intensity/frequency, and 8.3% reported total symptom resolution. The most common sources of CAM information were the Internet (76.5%) and recommendations from relatives or acquaintances (35.3%); only 5.9% of responders indicated a healthcare provider. The only factors associated with using CAM therapies was family income and parental education level.

Conclusions: CAM is relatively common among children with IBD. It does not affect the attitude towards conventional treatment and vaccination. Because the main source of information about CAM is Internet, there is a great need to educate healthcare practitioners about CAM methods in the treatment of IBD, in order to deliver help and professional advice to paediatric patients and their parents.

KEY WORDS:

complementary and alternative medicines, inflammatory bowel disease, children.

INTRODUCTION

Inflammatory bowel disease (IBD) is a group of chronic inflammatory diseases of the gastrointestinal tract with unknown aetiology. These include ulcerative colitis (UC), Crohn's disease (CD), and indeterminate colitis

(IC). Because their aetiology is not fully recognised, the conventional pharmacological treatment relies on anti-inflammatory and immunosuppressive drugs. However, the effectiveness of even the newest biological therapies is limited. In CD, 13–40% of patients are primary anti-TNF non-responders [1], and 23–46% develop secondary loss

ADDRESS FOR CORRESPONDENCE:

Marcin Dziekiewicz, Department of Paediatric Gastroenterology and Nutrition, Medical University of Warsaw, 63A Żwirki i Wigury St., 02-091 Warsaw, Poland, ORCID: 0000-0002-8465-3214, e-mail: marcin.dziekiewicz@wum.edu.pl

of response over time [2]. What is more, the treatment used is fraught with many side effects [3]. Therefore, patients are looking for other treatment methods on their own, which they consider more effective or more “natural” – with fewer side effects. In studies published so far, the frequency of using complementary and alternative medicine (CAM) in children with IBD reached as much as 90% [4]. However, there are significant differences between countries in terms of different cultural aspects or the availability of effective treatment methods. So far, however, no analyses have been published regarding this issue in Poland.

The aim of our work was to assess the frequency of CAM use in children with IBD, knowledge about them, and factors affecting the choice of these methods of therapy.

MATERIAL AND METHODS

Data was obtained based on an anonymous survey conducted among IBD patients referred to the Department of Pediatric Gastroenterology and Nutrition, Medical University of Warsaw and their guardians. Any patient with a diagnosis of CD, UC, or IC established according to Porto criteria was considered for the study [5]. The questionnaires were collected between March 2019 and September 2019.

The survey consisted of 22 questions. We collected demographic data, including the child's and parent age, sex, parental education level, and family income (rated on a scale of 1 to 4), the age of IBD diagnosis, and the effectiveness of previous IBD treatment (rated on a scale 1 to 5). In the part of the questionnaire regarding CAM, parents were asked to record the methods they had heard about and used in their children. The 39 types of CAM therapies were selected based on the analysis of Polish Internet forums for patients suffering from IBD. The full list is presented in Table 1. Parents were also asked about their attitude towards conventional IBD treatment and its replacement with CAM. The survey included an additional question about the child's current vaccination status.

Simple descriptive statistics for each variable were determined. The Pearson χ^2 test, Fisher exact test, and Mann-Whitney test were used for correlations. Data analyses were made using Statistica (Dell, USA) version 13.1.

RESULTS

Of the 40 patients with IBD who were invited to complete the questionnaire, three declined. The mean patient and parent ages were, respectively, 14.0 ± 3.2 years (range 5.4–17.9) and $40.2.2 \pm 5.1$ years (range 25–49). The mean disease duration was 3.7 ± 2.4 years. Seventy-five per cent of responders were mothers.

18/36 (50%) patients admitted that they had heard about the use of CAM in IBD. Of the 39 presented types of CAM, 37 (94.9%) were known by patients. Most often,

respondents mentioned the gluten-free diet ($n = 14$), linseed oil (11), lactose-free diet (10), fermented food (10), and linseed (10). The most commonly applied CAM were fermented food, oregano, and linseed (all 4/12, 33.3%). Detailed data are presented in Table 2.

CAM was applied by 12/37 (32.4%) patients in the past or is still used today. The only factors associated with CAM use were higher family income and higher parental education level (Table 3).

Effectiveness of CAM was assessed by 4/12 (33.3%) patients, of whom 3/12 (25%) noticed a decrease in intensity or frequency of symptoms, and 1/12 (8.3%) declared complete resolution of symptoms. The majority of patients in both groups declared that in the future they would consider using CAM, and this value was significantly higher among previous CAM users ($p = 0.02$).

The most common source of knowledge about the use of CAM in IBD was the Internet (13/17, 76.5%). 7/17 (41.2%) were looking for information in books or press, 6/17 (35.3%) got it from family members. 2/17 (11.8%) consulted with an alternative medicine specialist (not a medical doctor) and 1/17 (5.9%) with an attending physician.

The use of CAM did not affect conventional treatment. We found no correlation between CAM and the desire to stop conventional therapies. There were also no differences with respect to preventive vaccinations depending on the use of CAM. 19/37 (51.4%) patients

TABLE 1. A complete list of complementary and alternative medicine (CAM) therapies included in the questionnaire

Dietary intervention	Supplements	Other methods
Gluten-free diet	Boswellia	Acupuncture
Lactose-free diet	Kratom	Massages
High-protein diet	Ginkgo	Yoga
Low-fibre diet	Curcumin	Treatment method
Fermented foods	Ginger	Psychotherapy
Anti-inflammatory diet	Cinnamon	Hypnotherapy
Low-entropy diet	Rosemary	Homeopathy
SCD diet	Oregano	Hydrocolonotherapy
FODMAP diet	Herbs	Parasite therapy
	Honey	Non-virulent <i>E. coli</i> strains
	Linseed	
	Aloe vera	
	Coenzyme Q10	
	Linseed oil	
	Vitamin C in high doses	
	Vitamin D in high doses	
	DHA acids	
	L-glutamine	
	Iodine	
	DMSO	
	<i>Colostrum bovinum</i>	

SCD – specific carbohydrate diet, FODMAP – fermentable oligosaccharides, disaccharides, monosaccharides and polyols, DMSO – dimethyl sulfoxide

TABLE 2. A full list of known and used complementary and alternative medicine (CAM) therapies

Type of CAM	Known by patient	Used by patient
Dietary intervention		
Gluten-free diet	14	3
Fermented foods	10	4
Lactose-free diet	10	3
Anti-inflammatory diet	7	1
SCD diet	7	2
High-protein diet	6	0
Low-fibre diet	6	1
FODMAP diet	5	0
Low-entropy diet	1	0
Supplements		
Linseed oil	11	1
Linseed	10	4
Curcumin	9	2
Aloe vera	9	2
DHA acids	8	3
Ginger	7	2
Vitamin C in high doses	7	0
Honey	6	2
Rosemary	5	2
Oregano	5	4
Vitamin D in high doses	5	3
Boswellia	3	1
Cinnamon	3	1
Herbs	3	0
Kratom	2	0
Ginkgo	2	1
L-glutamine	2	0
Coenzyme Q10	1	1
DMSO	1	0
<i>Colostrum bovinum</i>	1	0
Iodine	0	0
Other methods		
Acupuncture	6	0
Massages	5	0
Yoga	5	0
Psychotherapy	5	3
Homeopathy	4	0
Parasite therapy	4	0
Hypnotherapy	2	0
Non-virulent <i>E. coli</i> strains	2	1
Hydrocolonotherapy	0	0

SCD – specific carbohydrate diet, FODMAP – fermentable oligosaccharides, disaccharides, monosaccharides and polyols, DMSO – dimethyl sulfoxide

were vaccinated according to the mandatory vaccination schedule, 15/37 (40.5%) were additionally vaccinated with non-obligatory vaccines, 2/37 (5.4%) declared that decided not to vaccinate their child without any medical contraindications, and 1/37 (2.7%) child was not vaccinated or was given only some of the mandatory vaccines due to medical contraindications.

DISCUSSION

Our study was one of the first to evaluate the frequency of CAM in children with IBD in a European country. It seems that this type of therapy is less popular in Poland than in other countries. To the best of our knowledge, our study for the first time assesses in children with IBD the relationship between the use of CAM and vaccination scepticism. We did not find such a relationship.

Knowledge about the use of CAM in the treatment of children with IBD in the population we analysed was moderate. Only 45.9% of respondents had ever heard of this method of treatment. However, among those who claimed that they never used CAM in their children, it was only 20% (5/25). There was a statistically significant difference in the number of known alternative medicine methods between CAM users and CAM non-users ($p = 0.01$). It can be presumed that patients using only conventional therapy did not look for information on alternative methods at all. The best-known methods were dietary interventions: gluten-free diet, lactose-free diet, and consumption of fermented foods. All those were also the most commonly used CAMs. Linseed oil and linseed were often mentioned but less frequently used. Both products are traditionally very popular in Poland, although their consumption has been falling in recent years. Among the little-known but often used were oregano, high doses of vitamin D, and psychotherapy. Vitamins, along with probiotics and long-chain polyunsaturated fatty acids (LC-PUFA), were also the most popular among patients from other countries [4, 6, 7].

In our population, 12/37 (32.4%) patients admitted they used CAM at the time of the analysis ($n = 8$, 21.6%) or in the past ($n = 4$, 10.8%). Data from other countries varied between 36% and 90% [4, 6–11]. CAM appears to be, relatively, the most popular among paediatric IBD patients in the US and Australia. In the studies by Day *et al.* [8] and Serpico *et al.* [10] it significantly exceeded half of the respondents and was, respectively, 72% and 84% with an average age of patients close to our population (respectively, 10.9 and 14 years old). In Southeast Asian countries, CAM's popularity was significant, at 76% in Malaysia and 90% in Singapore [4]. In Japan, it was estimated at 65% [12]. We identified one study in the European population. Nousiainen *et al.* analysed paediatric patients in Finland and evaluated the frequency of CAM use among them at 54% [7]. The observed differences can have several causes. First of all, other medical interventions are recognised as

TABLE 3. Differences between complementary and alternative medicine (CAM) users and non-users

Characteristic	CAM users (n = 12)	CAM non-users (n = 25)	p
Parental age (years, mean \pm SD)	42.4 \pm 5.85	39.1 \pm 4.66	0.09
Parental gender (male/female)	(5/7)	(4/21)	0.11
Education			0.02
University	10	9	
High school	2	10	
Elementary	0	2	
Other	0	4	
Place of residence			0.12
Warsaw	5	5	
City 50–200k population	3	4	
City < 50k population	3	5	
Village	1	11	
Family financial situation			0.04
Very good	5	6	
Good	7	8	
Average	0	11	
Bad	0	0	
Previous parental CAM use	3	1	0.09
Child's age (years, median [IQR])	14.0 (10.7–15.3)	15.2 (13.6–16.5)	0.17
Child's gender (male/female)	7/5	13/12	1.0
Disease duration (years, median [IQR])	3.3 (2.9–4.6)	3.0 (1.7–4.8)	0.43
Conventional treatment assessment			0.44
Very good	1	6	
Good	8	14	
Average	3	3	
Bad	0	1	
Very bad	0	1	
Vaccination assessment			0.41
Full schedule and additional	5	10	
Full vaccination schedule	5	14	
Partial vaccination schedule, because of medical reason	2	0	
Partial vaccination schedule, because of own decision	1	1	
Willingness to use CAM in the future			0.02
Definitely yes	3	1	
Rather yes	4	8	
I don't know	3	11	
Rather no	0	5	
Definitely no	2	0	
Willingness to give up treatment			0.14
Definitely yes	0	0	
Rather yes	1	1	
I don't know	3	2	
Rather no	3	16	
Definitely no	7	6	

SD – standard deviation, IQR – interquartile range

CAM in various countries or cultures. The list of alternative therapies used in each study was therefore different. For example, acupuncture, which is recognised as CAM in the US and European countries, is considered an element of conventional treatment in Asian countries. It may also be important that we did not consider probiotics as CAM. We assumed that some of them (e.g. VSL#3 or *Escherichia coli* Nissle 917) have scientifically proven effectiveness, were included in the ESPGHAN/ECCO recommendations for the treatment of ulcerative colitis in children [13], and are recommended in our centre to patients as part of conventional treatment. In many studies, however, it was the most commonly used alternative therapy [7, 9].

The general attitude to CAM in different countries can also be relevant. In the study comparing the use of CAM in various populations, Poland was the second from last country in terms of the frequency of CAM use with the weighted percentage 12.9 ± 0.9 , when in the whole of Europe it was 25.9% (95% confidence interval: 25.1–26.6) [14].

These data should be interpreted with caution. Our survey was anonymous. However, patients may conceal the use of CAM because it was not recommended by their physician; everyone pointed out that they always or almost always follow medical recommendations and possible negligence results only from objective reasons, not their own decision.

We identified only one factor correlating with the use of CAM. It was a greater level of parents' income. Surprisingly, there were no statistically significant differences between CAM users and non-users in terms of assessment of effects of previous conventional treatment. In other studies, it was an independent predictive factor [1, 6]. We also did not find any impact of parental CAM use, which was observed in other studies [6, 9].

Only four respondents commented on the effectiveness of CAM, and all of them described it positively. Interestingly, regardless of CAM use, only a few patients stated that they would not use CAM in the future. However, among CAM users there were significantly more of those who declared that they would “definitely” or “rather” use CAM in the future (0.75 vs. 0.36, $p = 0.02$).

The group we studied most often used the Internet as their primary source of knowledge. In comparison, in many other studies patients obtained their information from family and friends [4, 15, 16] and their primary practitioners [8, 10]. We believe that those differences may be an effect of a lack of trust in health care providers and other society members. In Poland the number of paramedics and non-medical pseudo-science propagators is on the rise. They mostly spread their beliefs and information about CAM through social media and other online platforms. According to data of the International Society Survey Profile, trust in health care providers in Poland is the lowest amongst the studied countries [17].

CAM practitioners often question the effectiveness of conventional medicine, including preventive vacci-

nations. This may create the risk of failure to use conventional medicine in favour of alternative treatment. In our study population, we did not find such a correlation. Only one patient in both groups declared that they were considering discontinuing conventional therapy in the future. All other participants denied this possibility. It is in line with previous data [18]. We also did not find any relationship between CAM and the tendency to give up preventive vaccinations. Such fears were raised by other researchers [19, 20]. This may be due to the fact that in our centre we attach great importance to preventive vaccinations, actively promoting their use among our patients.

The limitation of our study was the relatively small study population, although it was similar to some of the other studies [4, 8]. Another limitation is the lack of a control group. However, the primary aim of our study was to assess the frequency of CAM use among children with IBD in comparison to other countries. It is reasonable to repeat our research on a larger population, as well as to compare the use of CAM among children suffering from various chronic diseases.

CONCLUSIONS

In conclusion, the frequency of CAM use among children with IBD in Poland seems slightly lower than in other countries, especially non-European. On the other hand, nearly a third of the patients we surveyed use or have used CAM. For most, the main source of knowledge was the Internet. It is therefore necessary to talk openly with patients on this topic, also discussing the potential risks associated with CAM.

DISCLOSURE

The authors declare no conflict of interest.

REFERENCES

1. Ben-Horin S, Kopylov U, Chowers Y. Optimizing anti-TNF treatments in inflammatory bowel disease. *Autoimmun Rev* 2014; 13: 24-30.
2. Gisbert JP, Panes J. Loss of response and requirement of infliximab dose intensification in Crohn's disease: a review. *Am J Gastroenterol* 2009; 104: 760-767.
3. Beaugerie L, Rahier JF, Kirchgessner J. Predicting, Preventing, and Managing Treatment-related Complications in Patients With Inflammatory Bowel Diseases. *Clin Gastroenterol Hepatol* 2020; 18: 1324-1335.e2.
4. Ong F, Lee WS, Lin C, et al. Complementary and alternative medicine (CAM) practices and dietary patterns in children with inflammatory bowel disease in Singapore and Malaysia. *Pediatr Neonatol* 2018; 59: 494-500.
5. Levine A, Koletzko S, Turner D, et al. ESPGHAN revised porto criteria for the diagnosis of inflammatory bowel disease in children and adolescents. *J Pediatr Gastroenterol Nutr* 2014; 58: 795-806.

6. Heuschkel R, Afzal N, Wuerth A, et al. Complementary medicine use in children and young adults with inflammatory bowel disease. *Am J Gastroenterol* 2002; 97: 382-388.
7. Nousiainen P, Merras-Salmio L, Aalto K, Kolho KL. Complementary and alternative medicine use in adolescents with inflammatory bowel disease and juvenile idiopathic arthritis. *BMC Complement Altern Med* 2014; 14: 124.
8. Day AS, Whitten KE, Bohane TD. Use of complementary and alternative medicines by children and adolescents with inflammatory bowel disease. *J Paediatr Child Health* 2004; 40: 681-684.
9. Ceballos C, Bao R, Dunkin D, et al. Complementary and alternative medicine use at a single pediatric inflammatory bowel disease center. *Gastroenterol Nurs* 2014; 37: 265-271.
10. Serpico MR, Boyle BM, Kemper KJ, Kim SC. Complementary and Alternative Medicine Use in Children With Inflammatory Bowel Diseases: A Single-Center Survey. *J Pediatr Gastroenterol Nutr* 2016; 63: 651-657.
11. Wong AP, Clark AL, Garnett EA, et al. Use of complementary medicine in pediatric patients with inflammatory bowel disease: results from a multicenter survey. *J Pediatr Gastroenterol Nutr* 2009; 48: 55-60.
12. Uchida K, Inoue M, Otake K, et al. Complementary and alternative medicine use by Japanese children with pediatric surgical diseases. *Open J Pediatr* 2013; 3: 49-53.
13. Turner D, Ruemmele FM, Orlanski-Meyer E, et al. Management of Paediatric Ulcerative Colitis, Part 1: Ambulatory Care-An Evidence-based Guideline From European Crohn's and Colitis Organization and European Society of Paediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr* 2018; 67: 257-291.
14. Kempainen LM, Kempainen TT, Reippainen JA, et al. Use of complementary and alternative medicine in Europe: Health-related and sociodemographic determinants. *Scand J Public Health* 2018; 46: 448-455.
15. Oxelmark L, Lindberg A, Lofberg R, et al. Use of complementary and alternative medicine in Swedish patients with inflammatory bowel disease: a controlled study. *Eur J Gastroenterol Hepatol* 2016; 28: 1320-1328.
16. Fernandez A, Simian D, Quera R, et al. Complementary and alternative medicine in patients with inflammatory bowel disease: A survey performed in a tertiary center in Chile. *Complement Ther Med* 2018; 40: 77-82.
17. ISSP Research Group. International Social Survey Programme: Health and Health Care ISSP 2011. GESIS Data Archive CZDfV, 2015.
18. Weizman AV, Ahn E, Thanabalan R, et al. Characterisation of complementary and alternative medicine use and its impact on medication adherence in inflammatory bowel disease. *Aliment Pharmacol Ther* 2012; 35: 342-349.
19. Attwell K, Ward PR, Meyer SB, et al. "Do-it-yourself": Vaccine rejection and complementary and alternative medicine (CAM). *Soc Sci Med* 2018; 196: 106-114.
20. Bleser WK, Elewonibi BR, Miranda PY, BeLue R. Complementary and Alternative Medicine and Influenza Vaccine Uptake in US Children. *Pediatrics* 2016; 138: e20154664.