

## DIFFICULTIES AND FACTORS INFLUENCING PURCHASE DECISION. THE PERSPECTIVE OF FAMILIES WITH CHILDREN WITH AUTISM SPECTRUM DISORDERS ON A GLUTEN-FREE AND CASEIN-FREE DIET. PRELIMINARY STUDY

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### ABSTRACT

**Background.** Gluten-free and casein-free diet is frequently used in the support of therapy of children with autism spectrum disorders. In addition, many parents restrict the consumption of simple sugars for their children.

**Objective.** The aim of this paper was to understand factors influencing purchase decision in case of family with children with autism spectrum disorders on gluten-free and/or casein-free and/or sugar-free diet and the difficulties associated with this type of nutrition.

**Material and methods.** The study covered a group of 40 families with children with autism spectrum disorders (32 boys and 8 girls) aged 3 to 10 years. Data were collected with questionnaire included questions concerning overall characteristics of caregivers, availability of foods used in the special diet, factors affecting decision on the purchase of products, difficulties in maintaining the child nutrition method.

**Results.** The factors having strongest impact on parents' decisions on the purchase of products were product composition, presence of a certificate confirming the absence of gluten and/or milk and taste values. Exclusion diet constituted a considerable obstruction for traveling, social gatherings and resulted in conflicts with family and the environment. The limited range of healthy gluten-free, casein-free and sugar-free foods, low taste quality and unsatisfactory quality impeded purchase and preparation of varied meals.

**Conclusions.** The surveyed parents were aware consumers, paying attention primarily to product composition and safety. The respondents were looking for healthy, organic and nutritionally valuable products with low sugar content. Further development of the gluten/casein/ sugar free products market may considerably improve certain aspects of family's life with children with autism spectrum disorders.

**Key words:** *children with autism, gluten-free diet, casein-free diet, purchasing decision*

### STRESZCZENIE

**Wprowadzenie.** We wspomaganiu terapii dzieci z zaburzeniami ze spektrum autyzmu często stosowana jest dieta bezglutenowa i bezmleczna (bezkazeinowa). Wielu rodziców ogranicza także swoim dzieciom spożycie cukrów prostych.

**Cel.** Celem badania była ocena wymagań i preferencji konsumenckich rodziców dzieci z zaburzeniami ze spektrum autyzmu będących na diecie bezglutenowej i/lub bezkazeinowej i/lub bezcukrowej oraz trudności związanymi z takim sposobem żywienia dziecka.

**Material i metody.** W badaniu wzięło udział 40 rodziców dzieci z zaburzeniami ze spektrum autyzmu (32 chłopców i 8 dziewczynek) w wieku od 3 do 10 lat. Dane zebrano za pomocą ankiety zawierające pytania dotyczące m.in. ogólnej charakterystyki opiekunów, rodzaju stosowanej diety eliminacyjnej, dostępności środków spożywczych używanych w diecie specjalnej, trudności w utrzymaniu danego sposobu żywienia dziecka, czynników wpływających na decyzje o zakupie produktów stosowanych w diecie.

**Wyniki.** Czynnikiemami mającymi największe znaczenie dla respondentów przy zakupie produktów stosowanych w diecie dziecka były: skład produktu opisany na etykiecie, oznakowanie warunkujące wykluczenie glutenu i/lub mleka z pro-

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duktu oraz walory smakowe Dieta eliminacyjna wpłynęła negatywnie na różne aspekty życia codziennego respondentów, takie jak podróżowanie, spotkania towarzyskie, powodowała nieporozumienia rodzinne oraz konflikty z otoczeniem. Ograniczony asortyment stosowanej żywności specjalnej, niskie walory smakowe i niezadawalająca jakość zamienników żywności tradycyjnej utrudniały skomponowanie urozmaiconych posiłków.

**Wnioski.** Badani rodzice byli świadomymi konsumentami zwracającymi uwagę przede wszystkim na skład produktu i bezpieczeństwo. Respondenci szukali zdrowych, ekologicznych i wartościowych odżywczo produktów o niskiej zawartości cukru. Dalszy rozwój rynku produktów bezglutenowych, bezmlecznych i bezcukrowych może znacznie poprawić niektóre aspekty życia rodzin z dziećmi z zaburzeniami ze spektrum autyzmu.

**Słowa kluczowe:** *autyzm, dzieci, dieta bezglutenowa, dieta bezmleczna, decyzje o zakupie*

## INTRODUCTION

Autism is classified among neurodevelopmental disorders, referred to as autism spectrum disorders (ASD), characterized by autism triad, including inhibition of social development, disorders and dysfunctions in verbal and non-verbal communication as well as behavioral disorders [1]. The incidence rate of ASD have been continuously increasing globally for the last several decades. According WHO globally this disorder affects 1 in 160 people worldwide [2], whereby it should be noted that estimates of the US Center for Disease Control and Prevention the number of children in the USA is diagnosed with ASD increased from approximately one in 150 children in 2000 to one in 59 in 2014 [14]. These disorders do not have a single etiologic agent, but are caused by a set of different conditions of genetic and environmental background [17]. Digestive tract changes can be one of the factors favoring occurrence and intensification of neurological abnormalities. Some authors indicate that autistic children may exhibit abnormal digestion of gluten proteins and casein leading to formation of peptides with opioid properties (i.a.  $\beta$ -casomorphin from milk and gliadomorphin from gluten proteins) affecting the central nervous system function [16]. Gastrointestinal symptoms in ASD children may be caused by the commonly occurring in this group hypochlorhydria and reduced secretion of the gastric juice, lower activity of amylolytic enzymes and intestinal disaccharidases as well as mucosal inflammation of the stomach and intestines. Moreover, ASD patients have increased incidence of elevated permeability of intestinal mucosa and disorders of intestinal microflora [9, 15]. A suitable nutrition of ASD patients may have a considerable role in alleviating both digestion, metabolic and mental symptoms. Thus, apart from the primary psychological, educational and pharmacological treatment, attempts at dietary interventions were made. Gluten-free (GF) and casein-free diet (CF) are most frequently used in autistic disorders therapy, excluding consumption of gluten proteins and casein. It equals abandonment of consuming wheat, rye and barley based products as well as milk and its products,

and all products that may contain even traces of these ingredients. Given mentioned prevalence of autism spectrum disorder, families with children with ASD, next to a group of people with celiac disease are group potentially represents a significant customer group on the gluten-free market. A large proportion of parents also restrict consumption of simple sugars (SF-sugar-free diet) for their children, which aims at reducing overgrowth of yeasts *Candida albicans* in the intestinal flora, whose proliferation frequently disturbs ASD children functioning. There are about 50 thousand people with autism in Poland, with children representing 1/5 of that number [9]. No detailed data exist on the number of individuals with ASD in Poland and in the world using GF and/or CF diet. This is certainly an important group of consumers, but so far it has not been investigated.

The purpose of this paper is to understand factors influencing food purchase decision in case of family with children with ASD using GF, CF and/or SF diet and the difficulties associated with this type of nutrition.

## MATERIAL AND METHODS

The study was carried out between July 2017 and September 2018 at the Synergis Therapy Center in Warsaw (the institution dealing with the diagnosis and therapy of children with: autism, Asperger syndrome, pervasive developmental disorder and educational problems) and during 3 therapeutic camps for ASD children organized in Wisła by the Synergis Therapy Center and the Tourist Office „Tairon” (the office in Lublin dealing with tourism and rehabilitation of disabled people). There were two criteria for inclusion in the study: 1) parents of children diagnosed with ASD (by a psychiatrist according to the ICD-10 criteria [19]), 2). children on special restriction diet – GF and/or CF and/or SF for at least 6 month.

To obtain the data, the direct PAPI (Paper & Pen Personal Interview) survey method was used. The specifically developed, anonymous questionnaire was used consisted of 16 questions. It included a combination of one option, multiple-choice and open questions concerning, i.e. general characteristics of

the caregivers (age, education, place of residence) and on the use of exclusion diets in child, availability of food products, difficulties in maintaining the method of child nutrition, factors affecting decision on the purchase of products. To assess respondents' opinions on product availability and labeling, a 5-point hedonic Likert scale was used with the associated verbal terms, where 1 meant the lowest grade (difficult access/poorly labeled) and 5 - the highest (easy access/well labeled). The survey has been disseminated by the following channels: 1. Face-to-face: face-to-face interviews were done when it was possible, 2. E-mail: the survey was sent to the respondents by e-mail (after a previous personal or telephone call). Because of ability to reach the target group the study had a pilot character and was based on 40 completed questionnaires, out of 65 target respondents (61,5% return on correctly completed surveys). All participants gave their informed consent prior to inclusion in the survey and were informed of its purpose. Elements of descriptive statistics were used to analyze and present the results.

## RESULTS

The study covered a group of 40 families with children diagnosed with ASD (32 boys and 8 girls) aged 3 to 10 years ( $7,24 \pm 1,47$  years). The average age of boys was  $7,55 \pm 1,16$  years, while girls was  $6,0 \pm 1,87$  years. The questionnaire was filled by mothers (aged 32 – 46), because they are mostly engaged in the purchase of products used and preparation of meals. A considerable majority of the surveyed received higher education (88.9%) and the remaining had professional (11.1%). Over 77% resided in large cities (>100 000 residents), 11.1% in medium sized cities and the equal number in small cities ( $\leq 40$  000 residents). Among the respondents 90% did not belong to any associations and support groups for parents of ASD children. Parents participating in the study used various exclusion diets for their children (Table 1). The largest group (33 individuals) comprised of children using GF diet, including 10 children additionally using CF diet, and 22 on GF, CF and SF diet. The period of special diets ranged between 7 months and 7 years ( $49,98 \pm 21,49$  months). At times, parents added an additional exclusion diet to the nutrition model of their child, e.g. after a more detailed diagnosis of an allergy or gastrointestinal intolerance. Decision on the introduction of diet occurred at different times from the moment of ASD diagnosis (Table 2). Over half of the surveyed used exclusion diet along with ASD diagnosis or within the period of 1 year from the diagnosis. Some respondents pointed out to gastrointestinal problems of the child prior to the ASD diagnosis and used the diet due to allergy to dairy

Table 1. Type of exclusion diet (GF-gluten-free, CF-casein-free, SF-sugar-free)

Type of diet	Number of children
GFCFSF	21 (52,5%)
GFCF	10 (25%)
CFSF	4 (10%)
SF	1 (2.5%)
GFSF	1 (2.5%)
CFSF, no wheat	1 (2.5%)
vegetarian with gluten, milk and sugar restrictions	1 (2.5%)
GFCFSF, no eggs	1 (2.5%)

Table 2. Time of introducing of the exclusion diet in relation to ASD diagnosis

Time of introducing the diet	Number of answers
Before diagnosis	4 (10%)
along with diagnosis up to 1 year after diagnosis	21 (52.5%)
1-2 years after diagnosis	4 (10%)
2-3 years after diagnosis	4 (10%)
3-4 years after diagnosis	0 (0%)
4-5 years after diagnosis	12 (30%)

The number of responses does not sum up to 40 and 100%, because sometimes subsequent diet modifications were made by parents at different times to get ASD diagnosis

products. Thirty percent of parents started a special diet 4 to 5 years after ASD diagnosis.

A considerable majority of the respondents (72%) stated that the exclusion diet is solely used for ASD child, whereas in 17% families all members of the family switched to the special diet. In the remaining cases only mother with the ASD child or the child's neurotypical younger sibling were using the diet.

The Internet, scientific literature and health care personnel were primary sources of information on the used diet and food products (Table 3). In addition, 40% of respondents used the advice of a dietician.

Respondent's opinions were divided on the issue of labeling and access to food in the used special diet (Table 4). 25% respondents believed that access to such food products is easy, rather easy (15%) or sufficient (5%). 55% of parents were of the opposite opinion. Over 50% of the caregivers believed that GFCF and SF products are well labeled (17,5% - well, 27,5% -rather well, 7,5%- well enough), whereas the rest of the surveyed criticized this issue.

Due to the size of the sample, no in-depth analyzes were conducted regarding the customer behavior, nevertheless an important aspect of the conducted study was determination of what factors influence the

Table 3. Source of information on the used diet

Initial source of information	Number of answers
Internet	24 (60%)
Scientific literature	22 (55%)
Health care personnel	20 (50%)
Dietician	16 (40%)
Television	11 (28%)
Celiac society	4 (10%)
Other: therapist, diagnostic center	4 (10%)

The number of responses does not sum up to 40 and 100%, because one parent could provide several answers

child or during rehabilitation camps, gathering people from all over the country, who have access to different products.

Many respondents (17.5%) looked for products without gluten-free wheat starch, due the origin of the ingredient and the concerns about the insufficient purifying starch of gluten.

An additional element affecting product purchasing decision, important for 22% of the surveyed parents, was product's price.

Only 3 persons among the surveyed stated that they look for products labeled as bio/organic, the question whether they prefer foods from organic farming was met 80% positive answers. The most frequent reason

Table 4. Opinions on availability and labeling of food products in the used diet

Evaluated aspect	Value of the positions applicable for the assigned verbal terms (nr of indications and % share of indications of a given value)					Statistical measures		
	1- difficult	2- rather difficult	3- sufficient	4- rather easy	5- easy	Mean	SD	Median
Access	4 (10%)	18 (45%)	2 (5%)	6 (15%)	10 (25%)	3	1.43	2
	1- poorly	2- rather poorly	3- well enough	4- rather well	5- well			
Labeling	6 (15%)	13 (32.5%)	3 (7.5%)	11 (27.5%)	7 (17.5%)	3	1.38	3

decision of the parents on selection and purchasing food products used in the exclusion diet (Table 5). For 95% of the surveyed, food product composition described on the label was important. The majority of respondents (62.5%) further noted whether the given product possesses a certificate confirming the absence of gluten or milk in its composition. Half of the parents considered taste preferences of their child. A significant factor convincing the surveyed consumers about good quality of a product was its recommendation by their acquaintances. Such 'marketing' among parents of children with ASD often takes place during therapeutic classes for the

Table 5. Factors determining the choice and purchase of food products in the exclusion diet

Factors determining the choice and purchase of food products	Number of answers
Product composition - label	38 (95%)
Gluten-free/dairy-free certificate	25 (62.5%)
Taste preferences	20 (50%)
At the recommendation of friends	11 (27.5%)
Price	9 (22.5%)
Without gluten-free wheat starch	7 (17.5%)
Other: bio/ecolabeling	3 (7.5%)

The number of responses does not sum up to 40 and 100% because one parent could provide several answers

for selection of organic foods was the belief that this type of products is of higher quality, caused by lower contamination with chemicals and increased supervision by certification bodies. Parents, who provided negative answer to this question explained their opinion with high price of organic products (3 persons) and lack of access to such products (2 persons). Three respondents did not have opinion on organic foods.

The surveyed indicated different places for purchasing food products used in the diet. A considerable majority made purchases in 'healthy foods' shops (82.5%), at discount stores (77.5%) and on Internet (60%). Half of the parents purchased products necessary for the diet in supermarkets, and over 27% in delicatessen.

Introducing diet eliminating such popular cereals as wheat, rye, barley, often oats and dairy products requires obtaining a specialized knowledge and considerable organizational and financial effort. Such actions change life of the entire family and bring numerous difficulties (Table 6). The surveyed parents mostly complained about restricted possibilities of eating during travel. Only few restaurants, bars and hotels in Poland and abroad offer GF meals, and the additional dietary exclusions make eating out practically impossible. Even on rehabilitation camps for children with autism, where GFCFSF diet is considered, issues related to eating occur for various reasons. One of the reasons for difficulties

Table 6. Parents' experiences associated with the use of exclusion diet in their child

Difficulties in maintaining the diet	Number of answers
Eating out, during vacation, travel - lack of restaurants, bars with foods ensuring the diet, difficulties with purchasing food outside of home	23 (57.5%)
Lack of understanding from the society, diet disregarded by employees of pre-school facilities, other members of the family, e.g. grandparents or parent - primarily father (in the event of parents' divorce)	15 (37.5%)
Many products have a composition like the „periodic table”, they contain many E- ingredients	15 (37.5%)
Limited range, absence of suitable quality replacement products suitable quality, it is difficult to find products labeled as GFCFSF at the same time	12 (30%)
Taste values (typically problems with bread)	11 (27.5%)
Social isolation - own food has to be brought to gatherings, celebrations	7 (17.5%)
Siblings have sweets which are not allowed in the diet - great temptation and willingness to try, peers can eat food containing gluten/milk - feeling of one's difference	6 (15%)
Cooking in line with the diet for one child and “normally” for remaining family members	4 (10%)
Purchasing with child- the child chooses forbidden products	4 (10%)
Buying in various places – no full assortment in one shop	4 (10%)
Adaptation of diet products proportions in non-diet recipes	4 (10%)
Need for self-catering	4 (10%)
Limited access to products with healthy foods in smaller towns	4 (10%)
Difficulty in preparing varied foods	3 (7.5%)
Lack of diet meals at school canteen - difficult to adapt foods to the child's daily schedule	2 (5%)
Refusing the child food that he/she knows and used to eat before introducing the diet	2 (5%)

The number of responses does not sum up to 40 and 100% because one parent could provide several answers

of the diet is the poor products range resulting from higher cost of such foods and lack of knowledge of persons dealing with gastronomy. The second aspect of this situation concerns the ASD children. They often have an extremely limited number of acceptable foods, anxiety against novelties, sensory disruption, concentrate on details, rituals resulting from the anxiety and insecurity, further intensified by new place and unknown people.

Another serious issue pointed out by parents (37.5%) was the small selection of nutritionally valuable GFCF foods with low sugar content and simple composition (with the so-called clean label). The low diversity of these products was a major nuisance to caregivers (30% of respondents) who wanted to find quality diet replacements for traditional foods. In addition, the available products, especially bread, were assessed negatively by over 27% of parents and their children in terms of taste values.

Some surveyed parents (37.5%) experienced lack of understanding from their environment, including lack of agreement on the diet, e.g. with the kindergarten personnel or family members.

Due to difference of the diet, some of the respondents (17.5%) experienced sense of social isolation, particularly during social gatherings, various celebrations, caused by the need of bringing and consuming own food. The negative experiences

were also associated with purchasing products used in diet and the need of preparing meals by themselves, often cooking separately for ASD child and the rest of the family.

## DISCUSSION

Following the shock and breakdown caused by ASD diagnosis for the child, parents commence the combat for improvement of her/his functioning and enabling. Having a child with ASD, a disorder with unknown etiology, and often not accepting any therapy offered by the conventional medicine, forces parents to look for other solutions. ASD children caregivers often lean toward unconventional and alternative medicine [3, 18]. GFCF diet is one of the available solutions. Scientific research has not provided evidence for the need of routinely introduction of this diet to the therapeutic protocol of ASD patients, but some parents have observed its positive impact on autistic symptoms in their children [5, 18]. An adverse effect of introducing an elimination diet in children with ASD is the risk of deficiency of some vitamins (e.g. from group B) and minerals e.g. calcium, magnesium, zinc. This makes it difficult to balance the diet and is often associated with the need to use dietary supplements [5, 6, 9, 11]. In the present study, the information on the GFCF diet was primarily obtained by the surveyed parents from such media as the

Internet, television, scientific literature, and largely from health care personnel. This issue was not further detailed in the survey, but according to discussions with the respondents, the majority of physicians recommending GFCF diet belonged to DAN! movement (Defeat Autism Now!), pioneered by Dr. *Bernard Rimland* from the Autism Research Institute. Nowadays, this group of physicians raises much controversy in the medical community. Similarly, in the study of Cornish the majority of caregivers of ASD children learned about the possibility of trying the GFCF diet in the therapy of their children in television, the Internet, parent support groups, from friends and acquaintances. However, only 8% of the surveyed indicated the medical environment as the source of information on the diet. Regarding assistance during the use of GFCF diet, respondents also placed the primary care physician and pediatrician last, and chose to use the care of a dietitian (40%) and, to a considerable extent, support group devoted to autism [4]. 17 years later, in the study of Trudeau et al. health care professionals were the most frequent information source (65%) regarding the use of elimination diets and supplements in ASD treatment, however, it is not known to what extent these data relate to the GFCF diet itself [18]. ASD children caregivers often concealed the use of unconventional medicine therapy, including GFCF from the treating physician, primarily due to the reluctance of the medical community and lack of knowledge about therapies other than traditional [3, 18]. Furthermore, *Hozyasz* et al. raises the issue of physicians rejecting the possibility of considering gluten-free diet in juvenile patients with autism, which raised frustration and feeling of loss in their parents [8].

In the present study, over half of the respondents introduced exclusion diet for their child within 1 year from the ASD diagnosis. This is typically the most intensive time in terms of the search for suitable research, specialists and therapeutic methods. 30% of the surveyed parents made the decision about the diet at a later date, approx. 5 years after diagnosis. This could have been caused by too slow and/or lack of progress of the child in the conventional therapy used thus far or emergence of new problems. According to Hall and Riccio the child's functioning level is associated with selection of medical regimen, i.e. the more severe the form of autism, the more desperate caregivers are in seeking other, alternative solutions [7]. An increased length of time since the diagnosis may be associated with greater frustration among the families, giving risen to alternative medicine use.

The use of exclusion diet has a considerable impact on the daily functioning of the child with ASD and the entire family. A positive, expected effect means improved well-being of the patient, autistic symptoms alleviation, giving caregivers better motivation in overcoming the difficulties associated with

maintaining the special diet [4, 5]. In the present study, areas in which the parents experienced the greatest discomfort included: eating out, travels and lack of understanding from the society. A considerable obstacle in maintaining the diet consisted in the low range of products, their low nutritional and taste values and purchasing. Limitations to traveling and social gatherings were heavily underlined by caregivers of ASD children on GFCF diet in the study conducted 18 years ago [4]. This problem is still current and has been widely described in the literature on patients with coeliac disease on GF diet. However, in the case of patients with ASD the difficulties are greater, because diet is more stringent. Additionally, these patients constitute a particularly difficult consumer group due to strongly outlined culinary preferences, extremely limited number of acceptable foods, sensory and gastrointestinal disorders, schematism and focusing on details [21].

In our study efforts to maintain special diet were impeded by relatives or teachers for close to 38% of mothers. The respondents pointed out difficult relations with grandparents or ex-spouse, who did not agree on the diet and did not observe it when the child was visiting them. The surveyed individuals with coeliac disease faced the lack of support from the family to a lesser degree, and the understanding increased with the duration of the diet [20]. This likely stems from the fact, that gluten-free diet has been approved as the sole treatment of coeliac disease, whereas the use of this diet in autism therapy is a contentious issue in the medical community.

In the present study low selection of GFCFSF products, low taste values, particularly of bread and insufficient quality of replacements to the traditional diet were the sources of significant problems. According to Cornish, a wide range of food products and improved taste values are indispensable for the approval and maintaining GFCF diet in children with ASD [4]. An important factor affecting compliance with the diet is the physical availability of food, but also economic. This aspect is one of the particularly significant problems met by people using GF diet, indicated in numerous studies [4, 8, 10, 12, 13]. In Poland the cost of gluten-free food ration, assuming only the replacement of traditional cereal products with gluten-free components, increases by 30% [13]. In our study, price constituted an element determining decision on the purchase of a product for over 1/5 of the respondents, however, the high cost of special food was not seen as a factor causing difficulties in maintaining the diet. It is possible, that in terms of the material status, the group of parents participating in the study was not representative due to low number of respondents, who mostly received higher education and resided in large cities. Further research should

cover a more diverse group of respondents in terms of education and take into account the material conditions this type of families.

There are a couple areas to consider when examining the limitations of this study. While the study provides novel information about the selected aspects of daily life families with ASD children on GFCF diet, the study is limited as the all participants are from Poland, therefore may not be generalizable to other geographic regions. The number of participants was small and the survey was anonymous, but unlike other anonymous surveys, the authors had personal contact with each respondent and were able to discuss certain issues and doubts in more detail.

## CONCLUSION

The study results demonstrate that the surveyed parents were aware consumers, paying attention primarily to product composition and safety. They were looking for healthy, organic and nutritionally valuable gluten and casein free products with low sugar content. Further studies should examine whether this group of consumers correctly understands the information on the product label, or whether they can consciously choose healthy GFCFSF foods, e.g. find “hidden” sources of sugar. The exclusion diet had a considerable impact on various aspects of the daily life of respondents and their families, was a major obstacle in traveling, socializing and caused conflicts with family and the environment. The limited range of GFCFSF food products, their low taste values and unsatisfactory quality impeded composing varied meals and indicate the need for further development of the market of GFCF products including the special needs of this kind customers. This would give also greater possibilities to dietitians supporting families with children with ASD in choosing the right menu taking into account the specific nutritional, sensory and behavioral difficulties of each patient.

### Conflict of interest

*The authors declare no conflict of interest.*

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