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To cite this article: Bobbie L. Smith & Amanda K. Ludlow (2021): Patterns of Nutritional Supplement Use in Children with Tourette Syndrome, Journal of Dietary Supplements, DOI: [10.1080/19390211.2021.1958120](https://doi.org/10.1080/19390211.2021.1958120)

To link to this article: <https://doi.org/10.1080/19390211.2021.1958120>



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Published online: 11 Aug 2021.



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## Patterns of Nutritional Supplement Use in Children with Tourette Syndrome

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### ABSTRACT

Very little is known about the use of nutritional supplements in children with Tourette syndrome. The current study aimed to address the frequency of nutritional supplements and the use of special diets in children with Tourette syndrome and typically developing children. Additional data also sought to address the motivations behind using them, their cost and perceived benefits. A total of 76 responses from an anonymous online survey (Tourette syndrome=42; typically developing=34) were completed and analyzed. Fifty-six per cent of children with Tourette syndrome compared to 15% of typically developing children were currently taking nutritional supplements, with the majority take two or more. Thirty-five per cent of the Tourette syndrome compared to 6% typically developing were currently or had previously adopted a special diet. Supplements most used for children with TS included probiotics, omega-3, multivitamins and magnesium. For children with TS, supplementation often began around the age of eight, for a duration on average of 35 months. The average cost was £32.44 a month compared to £8.25 for typically developing children. Seventy-five per cent of supplement users in the Tourette syndrome group noted improvement, mainly in motor and vocal tics, sleep quality and anxiety reduction. Most caregivers learned of supplements through the Internet. In almost 42% of the Tourette syndrome group, their pediatrician was unaware of the supplement use and this rose to 65% for special diets. Given the popularity of nutritional supplements, more research on the effectiveness and safety of such interventions is crucial.

### KEYWORDS

diet; dietary supplement; magnesium; neurodevelopmental disorders; tic disorders; vitamins

## Introduction

Tourette syndrome (TS) is a neurodevelopmental disorder characterized by involuntary, repetitive and non-rhythmic motor and phonic tics (1). Treatment for TS focuses predominantly on comprehensive behavioral therapy, such as habit reversal therapy and exposure and response prevention. Despite behavioral interventions being reported as effective in reducing tics with minimal side effects (e.g. 2), there is limited access and availability to these therapies. Medication is another avenue of treatment, including alpha-agonists, often the first-line medication route for tics in the pediatric population,

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and antipsychotics being prescribed. However, such medication has been shown to treat TS with variable efficacy ratings (3) and can have many side effects, including weight gain, sedation and metabolic disturbances (4). Taken together, caregivers will often seek to explore alternative interventions to treat symptoms of TS with ease of access and minimal to no side effects (5).

Across the general population, there has been an increase in the use of alternative, non-westernised medicines primarily due to the increased accessibility and advocacy of methods *via* the Internet. For example, data from 2003 to 2006 showed that pediatric supplement use in various conditions ranged from 26% to 43% depending on age (6), and this is expected to have increased in recent years. Complementary and Alternative Medicines (CAM) are “diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional Western medicine” (7), p. V). However, due to the lack of standardized measures and a universal definition of CAM, there are no clear prevalence rates for CAM use. It is also essential to consider the results within the context of possible response bias of surveys in this field. A review found the average one-year prevalence of CAM use was 41.1% and the average lifetime prevalence was 51.8% in the UK with herbal medicine being the most commonly used CAM (8). However, these figures reduced when studies with poor methodology were excluded. CAM were found to be prevalent in 17.7% of children ( $n=1134$ ) in a UK sample (9). More specifically, CAM is more frequently used by children with a chronic illness, with increased prevalence for those who take medication regularly (10). For instance, CAM is increasingly being used by children with neurodevelopmental disorders (e.g. Autism Spectrum Disorder [ASD]; 11), and a study in a pediatric neurology clinic reported 44% of patients ( $n=105$ ) used CAM (12). The most reported types were chiropractic manipulation (15%) and dietary therapy (12%), and it has been reported that the majority of individuals who use CAM pay for the treatment themselves (13).

Nutritional supplements have become one of the most used CAM, they are consumed in addition to an individual's food intake and include minerals, vitamins and amino acids. Patterns and motivations for supplement use appear to vary in distinctive subpopulations. For example, in the general pediatric population, research has shown that supplements are taken to maintain and improve overall health, with multivitamins being regularly consumed (14). Further reasons include current trends, correcting nutritional deficiencies and allergies. Whilst 31% of children have been reported to take supplements (14), this percentage has been suggested to be higher in children with neurodevelopmental disorders. For example, it is reported that 51% of children with ASD are given nutritional supplements. A general multivitamin was the most commonly used, which mirrors the findings in children without a neurodevelopmental disorder (15, 16). Although, it has been suggested that multivitamin supplements should not be prescribed uniformly in children with high levels of food fussiness, particularly when results suggested that children with ASD did not receive sufficient supplementation for vitamin D and calcium to meet the recommended guidelines (16). These findings are parallel to food intake research showing a lack of vitamin D and calcium in children with ASD than typically developing (TD) children (17).

Anecdotal evidence has also suggested that children with TS to be increasingly likely to have changes made to their diet and to adopt the use of supplements. One possible reason for the increased reliance on the use of dietary measures in the TS community is the adverse side effects associated with medication which leads to a high proportion of patients discontinuing their medication (18). CAM is increasingly being used in conjunction with medication to help to treat symptoms, showing that caregivers seek to explore nonpharmacologic treatments in addition to the medication that has minimal or no side effects (5). Secondly, self-observations and beliefs that food can influence tic behaviors, for example, deterioration of tics have been related to consumption of refined sugar, caffeine and alcohol (19–21). Therefore, it has been suggested that the motivation for dietary intervention in a large proportion of individuals diagnosed with a neurodevelopmental disorder may be to reduce symptoms, in addition to overall health and wellbeing reasons.

The third reason for the increased use of nutritional supplements is to rectify imbalances in nutritional deficiencies. Research has reported heightened food fussiness and reduced preference for fruit and vegetables in children with TS (22), and such eating behaviors are associated with nutritional deficiencies (23). Moreover, it has been documented that daily tasks, such as eating, can become difficult due to the nature of tics (24). It is therefore important to understand similarities and differences in motivations for dietary changes between children with and without TS. A greater understanding will help to inform how future research explores CAM in this population.

Studies addressing the use of CAM in individuals with TS are limited. To our knowledge, there are only three studies to date that have specifically explored CAM use in individuals with TS. Of 100 patients with TS surveyed in America, 64% were CAM users, with 29% exploring more than three individual modalities (25). Twenty-one used vitamins, 15 used dietary supplements, and nine altered their diet. Motivations for CAM use in this survey included additional benefit to treatments prescribed by their doctor (35.9%), belief CAM is harmless (25%) and hopes for a cure (21.8%). Fifty-six per cent of participants with TS reported improvement from using CAM and, importantly, 80% of individuals who use CAM did not inform their doctor before first use. This research highlighted no differences, between CAM and non-CAM users, in terms of age, sex, race, income, medication use, side effects, general health or tic severity. More specifically, dietary modification was the most frequently used (42.6%) CAM among the 115 individuals with TS surveyed (26). One or more nutritional supplements to control symptoms were used by 87.8% of participants. The majority of which reported an improvement of tics. The most frequently reported supplement was the use of vitamin B, followed by frequent use of calcium, magnesium, vitamin C and/or vitamin E. However, both studies did not consider the interaction between medication and CAM and included both child and adult populations within their sample.

A recent study specifically focusing on CAM in children found 69.1% of 110 caregivers reported at least one form of CAM use (5). In terms of nutrition, herbal medicines were used by 18.2% and mega-vitamins were taken by 3.6% of CAM users, therefore providing conflicting results of the use of nutritional CAM in children with TS. Unlike previous research, 63% of respondents thought their physician would be supportive, and 58% informed their doctor about their child's CAM use. Overall, 93%

of CAM users reported a reduction in tic frequency. Therefore, considering some of the benefits of using CAM that have been noted, further research is needed to explore the use of dietary interventions and changes in children with TS.

Despite the lack of scientific evidence detailing any benefits, side effects and recommended doses, individuals with TS continue to explore the use of dietary changes in the maintenance of tics. Therefore, it is important to first understand what type of dietary interventions, if any, are being used, along with the motivations for use and outcomes. It is also important to consider if doctors were informed and the role they may have in informing patients of recent scientific literature. The current study aimed to describe the use and motivations of dietary supplements and changes in children with TS in comparison to TD children.

## **Method**

### ***Participants***

Seventy six caregivers, mothers, three fathers and three guardians, consented and completed questions on behalf of their child. In regard to marital status, 54 caregivers were married, 12 were cohabiting, three were divorced and seven were single. Forty-two children with TS between the ages of 5–17 years were included in the study. Caregiver reports were used to confirm children's TS diagnosis. A comparison group of 34 TD children aged between 6–17 years were included after five children were excluded due to having a neurodevelopmental disorder, such as ASD.

### ***Materials***

A survey, created on Qualtrics, was developed by the main researcher and their supervisory team. It was based on a similar survey developed to assess patterns of nutritional supplement use in children with Down syndrome, particularly types of supplements used, whether changes were observed, sources of information, cost and informing their healthcare professional (27). The survey was developed in mind of previous literature in this area. Demographic information on the respondent, including relation to child and age, and child, including weight, height, age, diagnosis and sex, were collected. This was followed by questions seeking to assess whether their child was using nutritional supplements and/or special diets and if so, their experience of using them. A mixture of closed and open questions was presented. For supplements and special diets, a range of options were given along with an 'other' option to ensure caregivers could provide as much information as possible. Supplements come in many forms, such as capsules, powders and gels, all of which were included in the study. As this research was an exploratory analysis, a broad definition of supplements was used in the current survey, with the only requirement being it was dietary. Special diets were defined as both diets that eliminated certain food or only contained particular food groups. To assess any change, caregivers were presented with some options ranging from general improvements to wellbeing to more specific options relating to their child's motor and vocal tic behavior. A text entry option was also available for caregivers to elaborate or

provide alternative changes that they had observed post-supplement use or through dietary changes.

### **Procedure**

Ethical approval was obtained from the University of Hertfordshire University Ethical Advisory Committee, protocol number: aLMS/PGT/UH/02784(4), and the research was performed in accordance with the Declaration of Helsinki. The survey was advertised through Tourettes Action, a United Kingdom-based charity that is the leading support and research for individuals with TS and their families. Tourettes Action provided non-financial support to support recruitment of this research. Advertisement at the University of Hertfordshire, social media and online local parenting forums were used to recruit caregivers of TD children. A link directed participants to the information sheet and consent form. Upon agreeing to take part, they were given access to the survey. The participants were fully debriefed and given contact details of charities who could help if they had any concerns regarding dietary patterns and/or other eating concerns.

### **Data analysis**

BMI z-scores (BMIz) for children were calculated using the Child Growth Foundation's (1996) growth references which adjust for age and gender. Frequency of nutritional supplement and special/restricted diet use in children with TS and TD children were tallied. Independent t-tests were conducted to explore differences in sex, age, medication use and BMIz between children with and without TS. Independent t-tests and chi-square tests of independence were conducted to explore differences in nutritional supplement and special diet use in children with TS and TD children and differences in medication use.

## **Results**

### **Participant characteristics**

Demographic characteristics of children with TS and children with TD is outlined in Table 1. Of the 21 children with TS taking medication, the most commonly reported was clonidine ( $n=3$ ) and sertraline ( $n=3$ ). There was no significant difference in age,  $t(74) = 1.92$ ,  $p = .059$ , or BMIz,  $t(46) = -1.13$ ,  $p = .263$ , between children with TS and TD children. There was a significant difference in sex,  $t(73) = -4.73$ ,  $p = .042$  between the groups.

### **Nutritional supplement use**

For children with TD, only five children (15%) were currently taking nutritional supplements. Of the four who detailed information on supplement use, two were taking two or more supplements. The number of children in each group who have taken the

**Table 1.** Demographic characteristics of children with TS and TD children.

Characteristics	TS	TD
N	42	34
Age(y)	M=11.84(SD=3.24)	M=10.32(SD=3.11)
Sex		
Male	33	10
Female	9	23
Body mass index z-score	.29	-.36
Medication		
Yes	21(53%)	3(9%)
No	20(47%)	31(91%)
Age of diagnosis(y)		
3-5	4	-
6-8	18	-
9-11	13	-
12-14	3	-
15+	4	-

given supplements is detailed in Table 2. The *other* supplements listed were a vegan mix of B12, omega-3, vitamin D and zinc. The mean age children started taking supplements was 11 years.

Of 43 children with TS, 24 (56%) were currently taking nutritional supplements. Of these 24 children, 14 (58%) were taking two or more supplements. The most common supplements were probiotics, omega-3, multivitamins and magnesium for children with TS. Other supplements included digestive enzymes, zinc, adrenoplex, boron betaine vitamin A, hemp oil ( $n=3$ ), St. John's wort and the amino acid N-acetylcysteine ( $n=2$ ). The mean age children started taking supplements was 8.5 years and the mean length of supplement use was 35 months. There was a significantly greater number of children with TS using nutritional supplements than TD children,  $X^2(1, N=76) = 13.77, p = .001$ .

For children with TS, two-tailed Pearson's correlations revealed that there was no significant relationship between number of supplements used ( $M=2.35, SD=1.40$ ) and years since diagnosis ( $M=3.12, SD=3.26$ ),  $r(22) = -.38, p = .085$ . Moreover, there was no significant difference in supplement use between those taking and not taking medication ( $p=1$ ).

**Table 2.** The number of children who have taken nutritional supplements.

Supplement	TS	TD
Omega-3	7(17%)	1(3%)
Probiotics	8(19%)	0
vitamin C	3(7%)	0
Vitamin B12	1(2%)	1(3%)
vitamin B	2(5%)	0
vitamin D	3(7%)	1(3%)
Selenium	2(5%)	0
Iron	1(2%)	1(3%)
Magnesium	8(19%)	0
Melatonin	6(14%)	0
Multivitamin	8(19%)	2(6%)
Calcium	0	0
Echinacea	0	0
Other	9(21%)	1(3%)

Of 24 children with TS using supplements, 18 (75%) observed changes after their child started taking supplements. Improved motor tics were noted in six children taking magnesium supplements and one taking melatonin. For improved vocal tics, magnesium ( $n=3$ ) and melatonin ( $n=1$ ) were also reported. Magnesium was also described to improve behavior ( $n=3$ ). Probiotics were described to improve behavior ( $n=3$ ) and improve social interaction ( $n=1$ ). A reported positive change in improved sleep pattern was mostly attributed to the use of melatonin ( $n=6$ ). Omega-3 was reported to have improved sleep pattern ( $n=2$ ), communication skills ( $n=1$ ), behavior ( $n=1$ ) and social interaction ( $n=1$ ) Additional positive changes reported include:

“easier ability to participate in activities”, “fewer mood swings” and “reducing anxiety improves mood and removes panic and then tics reduced”.

No notable changes reported for multivitamins ( $n=6$ ). Six caregivers reported side effects of supplements, which included flatulence, increased bowel movements, nausea and vivid dreams (from melatonin) and greasy hair (from omega-3). However, for all supplements used by TD children, there were no notable changes or side effects identified by their primary caregivers. Of the participants currently buying supplements, the average cost each month was £32.44 for children with TS compared to £8.25 for TD children.

### Special diet use

Table 3 details the number of children in each group who have tried a special diet. Of 43 children with TS, 15 (35%) were currently or had previously adopted a special diet. Of those using special diets in this group, six were taking medication and eight were not taking medication. There was no significant difference in diet use between those taking and not taking medication ( $p=.68$ ). Of 33 TD children, 2 (6%) were currently or had previously adopted a special diet. There was a significant difference in the number of children with using special diets compared to the TD children,  $X^2(1, N=76) = 17.34, p < .001$ . Other special diets for children with TS included avoiding food dye in their diet.

Of the 15 children with TS using special diets, 8 (53%) caregivers reported at least one positive change. The most common reported changes were improved vocal tics ( $n=8$ )

**Table 3.** The number of children who have adopted special diets.

Special diet	TS	TD
Gluten-free	4(10%)	0
Dairy-free	10(24%)	2(6%)
Yeast-free	0	0
Sugar-free	3(7%)	0
Egg-free	1(2%)	1(3%)
Specific carbohydrate diet	0	0
Feingold diet	0	0
Low GI diet	0	0
Addictive & preservative free	4(10%)	0
Caffeine-free	2(5%)	0
Other	2(5%)	0

and improved motor tics ( $n=8$ ), attributed to gluten-free (motor = 3, vocal = 2), dairy-free (motor = 3, vocal =4), and sugar free (motor = 2, vocal =2) diets. Gluten-free diets also improved social interaction ( $n=1$ ), sleep ( $n=1$ ) and behavior ( $n=1$ ). Dairy-free diets also improved social interaction ( $n=1$ ) and behavior ( $n=1$ ). Sugar-free diets also improved social interaction ( $n=1$ ) and behavior ( $n=2$ ). Additional observed changes reported include: “*Less agitated and less tummy issues*”, “*better mood*”, “*Slight improvement in nasal congestion*”, “*new tastes aggravated him and made tics worsen*” and “*happier and calmer*”. All caregivers of children with TD reported a positive change which was the absence of an allergic reaction. Dairy-free was reported to improve skin irritation caused by eczema, improved sleep and reduced pain caused due to intolerance. An egg-free diet was stated as preventing anaphylactic shock due to an egg allergy.

### **Nutritional supplements and special diets reasons for use**

For both supplements and special diets used in children with TS, improving symptoms of TS and to improve a child’s health were the most frequent reasons given (as shown in Table 4). For specific supplements, magnesium ( $n=7$ ) and omega-3 ( $n=6$ ) were mostly adopted to reduce children’s symptoms of TS. Probiotics ( $n=7$ ), omega-3 ( $n=5$ ) and general multivitamins ( $n=5$ ) were mostly adopted to improve their child’s overall health. Regarding special diets, gluten-free ( $n=7$ ) and dairy-free ( $n=5$ ) diets were adopted most often to reduce symptoms of TS. Dairy-free ( $n=5$ ) and sugar-free ( $n=5$ ) were the diets used most often to improve their child’s health.

There was several additional reasons for supplement use in children with TS, detailed as follows: anecdotal evidence for mineral balancing, digestive enzymes to avoid exclusion diet as already limited diet due to sensory issues, low vitamin D levels from blood tests, muscle pain and function, reduce anxiety and sense of hopelessness, to improve the immune system from the treatment of chemotherapy and antibiotics, belief immune system may be attacking neurological system, desperate to help tics, relaxation, and multivitamin to improve immunity from child’s fear of catching illnesses. Furthermore, “*too much cheese and sugar make her feel worse*” and “*When she has ice cream or hot chocolate, she often had really bad frequency straight afterwards (every few seconds)*”. Reasons for adopting a special diet include the child being lactose intolerance ( $n=2$ ), noticing changes in behavior after consuming drinks with sweeteners so avoided them, strong cheddar gave instant migraine, and one stated that their “*son tested intolerant so I hoped his tics might be caused by this (egg-free diet)*”.

**Table 4.** Reasons for using nutritional supplements and adopting special diets.

Reason for Use	TS		TD	
	Supplements	Special diets	Supplements	Special diets
To improve my child’s behavior	11 (26%)	8 (19%)	0	0
To reduce symptoms of TS	26 (62%)	16 (38%)	–	–
To improve my child’s health	27 (64%)	16 (38%)	5 (15%)	1 (3%)
Healthcare professionals’ recommendations	5 (12%)	10 (24%)	0	2 (6%)
To prevent nutritional deficiencies	5 (12%)	0	7 (21%)	0
To reach developmental milestones	0	0	0	0
Other	8 (19%)		0	0

In TD children, the most common reason for supplement use was to prevent nutritional deficiencies. This finding is consistent with one child becoming vegetarian and another a vegan. A healthcare professional's recommendation was listed most frequently for special diets due to all participants in this group being motivated by an allergy or intolerance to alter their diet.

### Information sources

The main sources of information for nutritional supplements and special diets for caregivers are summarized in Table 5. The main information source for nutritional supplements was the Internet, followed by parent support groups in the TS group. In contrast, general practitioners (GP) were the key source in the TD group. Other information sources for supplements included naturopath ( $n=1$ ), friend of pediatrician ( $n=1$ ), internet (medical papers,  $n=1$ ). Other sources for special included naturopath ( $n=1$ ), parent-observation ( $n=3$ ), parent is a dietician ( $n=1$ ).

### Physician communication

The frequency of caregivers informing their (GP) or pediatrician about their child's nutritional supplement and diet use was recorded. Results are shown in Table 6. The majority of caregivers did not inform their GP because the GP did not ask them in children with TS. Other reasons included: "no support or advice from GP when asked for nutritional support", "didn't think they would be interested" ( $n=2$ ), "they don't care", "don't see them enough", "told consultant but reaction was no medical evidence so not a recognised treatment for TS". A chi-square test of independence revealed that caregivers informed their GP of supplement use when their child was taking medication than children not taking medication,  $X^2(1, N=34) = 14.49, p < .001$ .

For TD children, three caregivers did not inform their GP of their child's supplement use. In addition to the reasons outlined in Table 6, one caregiver did not inform their GP because their child was "taking the supplement due to becoming vegan and is healthy".

**Table 5.** Primary sources of information for supplement and special diet use in children with TS and TD children.

Information sources	TS		TD	
	Supplements	Special Diets	Supplements	Special diets
Television	1	0	0	0
Website	19	4	1	0
Magazine	2	0	0	0
Parent support group	9	3	0	0
Relatives and friends	7	2	1	1
GP	6	3	3	2
Dietician / Nutritionist	4	2	0	1
Book	3	4	1	0
Alternative healthcare professional	1	2	1	0
Other	4	5	0	0

**Table 6.** Frequency of informing GP of nutritional supplements and special diet use, and reasons for not.

	TS		TD	
	Supplements	Special diets	Supplements	Special diets
Informed GP:				
Yes	14(58%)	5(33%)	2(6%)	2(6%)
No	10(42%)	10(67%)	3(9%)	0
Reasons for not informing GP:				
GP did not ask	8(19%)	7(17%)	1(3%)	–
Did not think they would approve	1(2%)	0	0	–
Not prescribed medicine	4(10%)	2(5%)	1(3%)	–
Other	7(17%)	5(12%)	+1(3%)	–

## Discussion

The current study aimed to describe the use and motivations of nutritional supplements and any subsequent observed changes in children with TS in comparison to TD children. The results suggest that children with TS use nutritional supplements and special diets significantly more often than TD children. For example, 72% of children with TS in the current study used nutritional supplements and/or a special diet, showing nutritional changes are common. Motivations for dietary changes in children with TS focus on improving general health and specific tic-related symptoms, and some positive changes observed for tic-related symptoms were observed.

The nutritional supplements found to be taken most by the children with TS diagnosis were magnesium, multivitamin, probiotics and omega-3 fatty acids. These findings are similar to those found in children with ASD (28). Research regarding the effectiveness, efficacy and safety of using these supplements requires further investigation. For example, there are no studies to date assessing the effectiveness of probiotics, multivitamins or magnesium in children with TS. Probiotics are bacteria that help to maintain positive gut health and can also regulate inflammation and immune function. Studies have indicated that TS has been associated with imbalances in the gut microbiota (29). While, children commonly take multivitamins, often to maintain health and prevent deficiencies (14), the effectiveness of these supplements has yet to be investigated addressing symptoms of TS. However, preliminary studies on comorbid disorders, such as ASD, show improvement in core symptomology (30, 31). In the current study multivitamins and probiotics were mainly taken to improve children's overall health; however, no notable changes were observed for multivitamin consumption. For probiotics, there was some improvement in behavior and social interaction observed by caregivers.

One supplement, omega-3 fatty acids, has been tested in a randomized, double-blind, placebo-controlled trial of children with TS, finding no direct effect on tic reduction, anxiety or depression (32). However, the experimental group did have an overall mean improvement on the Yale Global Tic Severity Scale (YGTSS; 33), with authors suggesting that a diet with high levels of omega-3 fatty acids may help alleviate some tic-related impairment for some children with TS. Although there was no direct influence on tic frequency or severity, there is increasing evidence of the role of omega-3 in improving associated tic-related symptoms. This is consistent with the current findings showing

omega-3 helped with social interaction, behavior and sleep patterns. Despite this, results need to be interpreted with caution in acknowledgement of the very small sample size.

In relation to tics, magnesium was reported to improve both vocal and motor tics. Magnesium is a mineral that has a critical role in many aspects of body regulation and functioning, including regulating muscle and nerve function, blood pressure and blood glucose control (34). Importantly, a magnesium deficiency has been suggested as being commonly reported in children with TS and anecdotal reports suggest a reduction in symptoms when taking magnesium supplements (35). Consistent with this, some caregivers noted that magnesium needed to be continuously taken for symptoms to remain improved. A deficiency of magnesium leads to symptoms, such as fatigue, migraines, depression, muscle spasms (36), which mirrors that found in other neurodevelopmental disorders, such as ASD. Randomized controlled trials need to be conducted to assess the effectiveness and efficacy of using magnesium in the treatment of TS (37).

Regarding special diets, motivations were consistent with those given for supplement use in this study. A dairy-free diet was the most common diet to be tried, and caregivers reported improvements in vocal and motor tics. This finding of eliminating dairy, additives, sugars, and gluten has been found to be increasingly common in children with neurodevelopmental disorders. In the case of TS, reports from individuals and caregivers of children with TS indicate deterioration in tic symptoms when they reduced consumption of coke, coffee, black tea, preserving agents, refined white sugar and sweeteners (20). Future research needs to consider supplement use in conjunction with diet to assess the individual's overall intake and its association with core symptomatology. Furthermore, motivation for using CAM is demonstrated through caregivers' willingness to pay for supplements. This finding raises an additional ethical issue and reinforces the urgency for further research to establish the efficacy and effectiveness of supplements.

A significant number of caregivers of children with TS did not inform their general practitioner or pediatrician of their child's supplement and/or special diet use. Although children taking medication informed their general practitioner of their supplement use more often, this remains problematic for many reasons and the combination of dietary changes and medication needs to be considered. For example, in children with ASD, it has been found that they rarely need most of the micronutrients they are commonly given as supplements, leading to an excess intake (16). Furthermore, consumption of unregulated supplements can have adverse effects, such as an overdose of fat-soluble vitamins and hepatotoxicity. It is especially important as some products do not list ingredients in contrast to regulations (38).

Like the findings by (25), many caregivers did not inform their general practitioner. Reasons provided by the current sample of parents with TS included because they did not ask; it was not considered prescription medicine, or they did not take an interest in alternative interventions. A simple solution to encourage caregivers to share details would be for healthcare professionals to ask patients about their supplement use. It is possible that without asking they are missing information required for optimal healthcare. It is not only important to consider the dose of supplements in future research

to establish effectiveness, but also in clinical practice. Healthcare professionals will then be able to provide guidance based on medication use, current diet, recommended daily intakes and any relevant information on the adverse effects of consuming micronutrients in excess.

In addition to improving their child's health, there was a strong motivation to make nutritional changes to improve disorder-specific symptoms in the TS group. The positive effects observed by caregivers imply that nutritional changes could help reduce specific and associated symptoms TS. Taken together, this research suggests that caregivers are interested and willing to spend money on and make nutritional changes, in terms of supplements and special diets, and have reported some benefits. This suggestion is consistent with research finding families with a child with developmental disabilities want their doctors to inform them of CAM options (39).

There are important scientific and clinical implications of this research. Firstly, rigorous research is needed to explore the effectiveness and safety of dietary changes and supplements. Many families continue to use supplements with only little to no scientific research, particularly in children with TS, as many CAM are often viewed as natural and harmless (40). Although, it is also important to consider the difficulties of research as there are no set regulations for CAM and individuals are using methods in different ways (41). Secondly, research should be transformed into easily accessible educational materials to help families make informed decisions regarding their child's diet. Thirdly, healthcare professionals need to be informed of the latest CAM research and be willing to discuss options openly with families. A holistic, patient-centred approach is encouraged in a supportive, nonjudgmental environment. Lastly, healthcare professionals need to consider diet and supplements concerning medication use, nutritional deficiencies, food intake and weight. Greater understanding of supplement use, as investigated in the current study, allows to interpret better changes after supplements and special diets and personalize their use if such changes were to be confirmed in clinical trials or larger observational studies. This is particularly relevant given the knowledge of the baseline dietary profile of individuals with TS is extremely limited.

It is important to note the limitations of the current study. Previous CAM research has been criticized for including a large proportion of participants with a high socioeconomic status who can self-finance CAM themselves (e.g. 25). The sample size in the current study also lends itself to criticism as it not only inhibits the generalizability of the findings but also fails to provide important information about any demographic differences between children taking supplements and/or special diets and those who are not. Therefore, the reported benefits of CAM in lower socioeconomic status groups remain unclear (26). Although, a recent study found no significant difference in age, gender, caregiver age, marital status, race and education level between CAM and non-CAM users (5).

Another limitation is the possibility that the volunteer sample lead to only individuals with a keen interest in nutrition and CAM to complete the survey, meaning that participants may deem these methods to be effective or have strong opinion on them. Also, caregivers who have been using supplements and diets but have not felt comfortable informing their clinician may have not felt comfortable participating in the

current study. Furthermore, the self-report nature of the study does mean that positive changes were subjective.

This study presents preliminary findings that nutritional supplements and special diets are being used in children with TS, with many caregivers noticing positive changes. Given that many parents are voluntarily choosing to use supplements for their children with TS, there is a clear need for future research to confirm these findings in a larger sample and produce robust results on the effectiveness and safety of such dietary interventions.

## Clinical significance

Families are continuing to use nutritional supplements as a form of CAM, despite there being a lack of scientific evidence. Therefore, there is a need for research to understand the effectiveness and efficacy of these supplements. Furthermore, healthcare professionals need to be informed of the latest CAM research and be willing to discuss options openly with families. It is important also to consider nutritional supplement use in the context of children's eating behavior, food intake, weight status and medication use.

## Acknowledgements

The authors wish to thank the families who participated in the study. The authors are also grateful to Tourettes Action and Dr Seonaid Anderson for their help with advertising the study.

## Disclosure statement

The authors declare no conflict of interest.

## Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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