

Patterns of Dietary Supplement Use in Children with Down Syndrome

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Objective To determine the frequency of dietary supplement use for children with Down syndrome, and to obtain additional descriptive data regarding the age of initial treatment, cost, perceived benefits, and disclosure of use to the pediatrician.

Study design An anonymous questionnaire in English and Spanish was created for parents of children under age 18 years with Down syndrome. Surveys were completed in our clinic, or accessed on a number of Down syndrome-related websites.

Results A total of 1167 responses were completed and analyzed. Forty nine percent of responders currently/ previously gave their child supplement(s). The average child received 3 supplements (ranging from 1-18). Although Nutrivene, curcumin, and green tea extract were most common, over 150 different products were reported. Supplementation began most often in infancy, generally between age 4 and 6 months. Average cost was \$90.53/month. Overall, 87% of users noted improvement, mainly in speech, immunity, and attention; 17% reported side-effects, predominantly gastrointestinal disturbance. Lack of improvement and cost were the main reasons for discontinuation. Most parents learned of supplements through a parent group or friend. In almost 20%, the pediatrician was unaware of the supplement use.

Conclusions Almost one-half of parents surveyed administer or have administered supplement(s) to their children with Down syndrome. Many of the supplements have concerning ingredient profiles and are given to children too young to articulate potential ill effects. Providers need to be aware of these products and question families about their use. (*J Pediatr* 2018;■■:■■-■■).

Dietary supplements are commonly used in both children and adults to promote health and wellness. A study which evaluated data from 2003 to 2006 showed that pediatric supplement use in various conditions ranged from 26% to 43% depending on age, but did not assess use in infants.¹

Dietary supplements are also used in children with Down syndrome, often with the specific hope of improving intelligence or function. Dietary “treatment” for Down syndrome was first proposed in the 1940s when Henry Turkel created a supplement containing almost 50 ingredients and reported improvements in his patients’ intelligence and appearance.² One ingredient was thyroxine, which in fact may have benefited those with hypothyroidism. Since that time, a number of others have used various combinations of vitamins, minerals, antioxidants, and other ingredients to try to improve the intelligence of affected children. Some have reported not only a functional improvement, but physical changes in the children being treated, including the development of a typical nose bridge and reduction of epicanthal folds.^{3,4} Nutrivene-D (International Nutrition, Inc, Middle River, Maryland) is a multi-ingredient formula featured on television in 1995 and again in 1997 in stories regarding Dixie Tafoya and the formula she created for her adopted daughter with Down syndrome.^{5,6} She expanded on Turkel’s formula and added the drug piracetam (Pure Nootropics, Albuquerque, New Mexico). None of these products, however, have been proven to be effective.^{5,7,8} Policy statements by patient advocacy groups and professional organizations have clearly declined to support supplement use for individuals with Down syndrome because of the lack of proven benefit and safety.^{9,10}

Over time, the number of products touted to improve health and intellectual function has continued to increase. These products contain hundreds of substances, alone or in combination, including antioxidants, herbs, vitamins, minerals, essential oils, enzymes, and animal/plant products. As nutritional supplements are typically not prescribed by physicians, it is difficult to ascertain the frequency of their use. When asked only what medications their child takes, parents may not report supplements. This study was, thus, designed to learn more about the overall frequency of supplement use, the types of supplements that are being used, and the frequency at which families disclose the supplement use to their primary care provider.

Methods

A survey was created in English and Spanish on [SurveyMonkey.com](https://www.surveymonkey.com) to ask parents about their awareness and use of nutritional supplements for children with Down

ECGC Epigallocatechin-3-gallate
DV Daily value

From the Children’s National Rare Disease Institute, Children’s National Health System, Washington, DC

The authors declare no conflicts of interest.

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syndrome ([Appendix](#); available at [www.jpeds.com](#)). The only inclusion criterion was having a child under age 18 years diagnosed with Down syndrome. The survey was anonymous and was declared exempt from requiring approval by our Institutional Review Board. Some parents took the survey on a tablet device in our clinic; others accessed the survey online. Direct links were provided on the websites of the National Down Syndrome Society, National Down Syndrome Congress, DS-Connect, and the Down Syndrome Association of Northern Virginia. Permission was given to parents who asked to share the link on various Facebook pages to encourage participation.

After choosing their preferred language and confirming that they have a child under age 18 years with Down syndrome, participants were asked to select 1 of the following responses: (1) I currently use supplements for my child with Down syndrome; (2) I am not currently using the supplements, but have used them in the past; (3) I have never used supplements, although I have heard about them; or (4) I have never heard of nutritional supplements for Down syndrome. Those that selected option 4 were asked their race/ethnicity and thanked for their participation; no additional questions were asked. Each of the other 3 responses led participants to a different subsurvey based on this answer. Therefore, not all participants were asked the same number of questions.

Responses did not identify from which source (clinic, DS-Connect, National Down Syndrome Society, etc) the survey was accessed. However, it was most likely that more than one-half of our responses came via DS-Connect, the Down syndrome registry launched by the National Institutes of Health as a research tool. This is because our total number of respondents more than doubled after being made available to DS-Connect users. Participants who did not complete the question regarding supplement use were disqualified from data analysis.

Results

We received over 1200 responses; 1167 were considered complete for analysis. Although the majority of respondents were from the US, some respondents lived in Brazil, Poland, England, and the European Union. 98% were English speaking; 2% of participants completed our Spanish survey. The vast majority (82.5%) listed their race/ethnicity as Caucasian; a much smaller percentage identified as African American or Asian (4.5% each), Hispanic or Middle Eastern (3% each), mixed ethnicity (0.75%), Native American (0.5%), or other (1%). The respondents' children ranged in age from infancy (4.2%) to older children (12-17 years of age; 25%). There was an almost even distribution of about 15% for age groups 13-35 months, 3-4 years, 5-6 years, and 7-9 years; 9% were age 10-12 years.

Approximately one-third (37.9%) of parents reported that they currently use dietary supplements for their child with Down syndrome. Another 11.6% have used them in the past. Those that had heard of these supplements but have not used them accounted for 33.6% of our sample, and 17.0% were not aware of these supplements at all.

Supplements Used

A tremendous variety of supplements were reported. Many are brand-name combinations of multiple ingredients, making classification into discrete categories more difficult. A number of supplements listed by parents are actually prescribed medications. Others could not be classified because no product by that name could be found, or were nonspecific ("various homeopathy" or "others based on labs"). Others listed nutritional formulas or laxatives. Some of the more unusual supplements included camel milk, bee pollen, royal jelly, and hemp oil. A full list of products reported is shown in [Table I](#) (available at [www.jpeds.com](#)), along with definitions of some less familiar product categories.¹¹⁻¹³

On average, children received a combination of 3.3 different supplements, with a range of 1-18. The single most commonly used supplement (13.6%) was Nutrivene-D. Nutrivene-D is actually a product line, including Daily Supplement, Daily Enzyme, NightTime Formula, and Polyphenol Support. Those who reported Nutrivene-D use may have been using 1 or more of those products. Curcumin, produced from the turmeric plant and reported to have antioxidant and anti-inflammatory properties, was next most common at 9.6%. Green tea extract, or its active ingredient epigallocatechin-3-gallate (EGCG) was cited by 8.7%.

If categories of supplements are considered, the most popular group would be antioxidants (25.8%). This is not surprising, as that category contains both curcumin and green tea extract/EGCG. The second most common group was vitamins, accounting for 18.9%. This included both single and multivitamins. When a single vitamin was noted, the B vitamin family was most frequent, especially the folate/folic acid/folinic acid forms of B9. Third most common were the various combination or proprietary products at 15.8%. These included Nutrivene-D and High Achievement Potential Capsules (Warner House, Inc, Tucson, Arizona). Supplementation with fats/fatty acids accounted for 10.8%. This group included fish oil, as well as the omega 3, 6, and 9 fatty acids.

Timing of Supplementation

Parents were asked at what age they began giving nutritional supplements to their children. There was a wide range of answers ([Figure](#)), with some women taking the supplements themselves while pregnant with a fetus prenatally diagnosed with Down syndrome. Others took the supplements themselves, providing them to their child through breast milk. Of those parents who gave supplements, 28.4% began before their child's first birthday. After infancy, the second most common age was 12-23 months, when 17.5% began supplementation. There was a drop-off after 4 years of age. Of those parents who chose to try dietary supplements, two-thirds (66.5%) had done so by that time.

Cost

Although 1 parent reported spending \$3000/month, all others reported spending between \$15 and \$400 monthly. (Amounts stated in foreign currency were converted to American [US] dollars). On average, parents spent \$90.53/month on their chil-

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