Facial Effects of the Warner Protocol for Children with Down Syndrome

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Abstract

Background: Children with Down syndrome tend to have unique facial characteristics which make them identifiable on the basis of appearance only. Since 1986, Dr. F. Jack Warner has specialized in seeing people with Down syndrome. Warner uses an unconventional protocol which includes interventions such as nutrition (HAP Caps, flaxseed oil, N, N-dimethylglycine), physical therapy, ophthalmology, and conventional medicine. Warner claims his interventions can help make children with Down syndrome more like non-Down's children. The purpose of this investigation was to determine if the Warner protocol can improve facial features for children with Down syndrome.

Method: This investigation used a pretest-posttest, natural control group design. An independent investigation of a random sample of Warner's records was performed. Warner has two photographs taken at the initial appointment, a front photograph and a side (profile) photograph. Facial features of children who visited the Warner House were magnified and analyzed based on the initial photographs in the file and the final photographs in the file.

Results: An analysis of the sample suggests that the combined interventions appear to significantly improve facial features for children with Down syndrome.

Conclusion: Nutrition may be the most likely intervention to be credited for improving facial features. A prospective study to test this position should be performed.

Introduction

Down syndrome is the result of total or partial triplication of the 21st chromosome.[1] "The diagnostic clinical features of this condition are usually readily evident, even at birth. The flat facial profile, oblique palpebral fissures, and epicanthic folds account for the older designations of "mongolism" and "mongolian idiocy."1 "These patients also have immune defects and an increased susceptibility to leukemia as well as greatly enhanced probability of Alzheimer's disease (presenile dementia) as young adults in the third decade. Essentially nothing is known about how one extra chromosome 21 could have such profound effects."[2] A quantitative study decades ago concluded "that all areas of the face and skull are deficient in persons with Down's syndrome."[3]

Surgery has been used by some children with Down syndrome to help them have a more normal appearance. Although parents tend to believe their children have improved, most independent reviewers have felt there was no discernible improvement from this type of cosmetic surgery.[4-6]

Since 1986, Dr. F. Jack Warner (MD) has specialized in seeing non-institutionalized patients with trisomy 21. The Warner House uses a multi-disciplinary approach with interventions including nutrition, medicine, physical therapy, and opthamology. Dr. Warner has seen thousands of patients who suffer from trisomy disorders, but because many of these patients are seen only at traveling clinics, follow-up records do not exist on all the patients. All Warner House patients, or their legal guardians, sign a consent form allowing data to be included in published reports. This investigation was intended to determine if the Warner interventions might have any efficacy on facial features and to determine if further research would be warranted.

Materials

The nutritional interventions used by Warner House are a combination of a multiple vitamin/mineral formula called "HAP

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Caps" (HAP stands for Health and Progress), plus flaxseed oil (1-3 teaspoons normally recommended), N,N-dimethyl-glycine (an amino acid derivative, with 30-500 mg normally recommended), and sometimes other nutritional substances. Each HAP Caps capsule contains beta carotene 2000 I.U., vitamin B_1 6.25 mg, vitamin B_2 6.25 mg, vitamin B_3 6.25 mg, calcium pantothenate 25 mg, vitamin B_6 6.25 mg, vitamin B_{12} 1.25 mcg, vitamin C 100 mg, vitamin D_3 33 I.U., biotin 25 mcg, vitamin E 33 I.U., choline 50 mg, folic acid 50 mcg, inositol 5 mg, PABA 75 mcg, cobalt 5 mcg, iron 5 mg, manganese 125 mcg, copper 40 mcg, molybdenum 75 mcg, selenium 7.5 mcg, zinc 2.5 mg, organic iodine (from kelp) 18.75 mcg, rutin (a bioflavonoid) 25 mcg, quercitin (a bioflavonoid) 6 mg, liver extract (bovine) 6.25 mg, betaine hydrochloride 1.8 mg, ox bile 3.6 mg, pancreatin (supplies enzymes) 2.8 mg, co-enzyme Q_{10} 8 mg, and the amino acids glutamine 75 mg, taurine 4 mg, and tyrosine 55 mg–the number of capsules recommended varies by patient weight[7] and normally ranges from 2-12 per day (approximately 1 HAP Cap per 10 lbs.). HAP Caps have a similar composition to the 'U' series nutrients that Dr. Turkel pioneered decades previously (which Turkel safely used for thousands with Down syndrome).[8] The Warner House recommends physical therapy for all trisomy patients. It also advises that all with trisomy 21 disorders avoid cow's milk products. Ophtha-mological interventions, interventions for infections, thyroid medications, and other conventional medical interventions are recommended when indicated.

Method

At Warner House, two photographs are taken at the initial appointment, a front photograph and a side (profile) photograph by a staff member; follow-up photographs are normally taken by the same staff member or sometimes is sent in by the parents. This specific investigation used a pretest-posttest, natural control group design.

Facial features were analyzed by reviewing photographs under lighted magnification. The three features assessed were degree of facial swelling, development of a nose bridge, and epicanthal folds of the eye. "The face of a person with Down syndrome is characterized by flatness and small centrally placed features. The flatness is accentuated by the broad, flat nose...flat-bridged nose."[5] Down's patients have been described as an having an "underdeveloped midface" while Down's infants have been described to have 'chubby cheeks"[5] and "facial edema" has also been noted.[9] "Epicanthal folds are defined as a fold of skin covering all or part of the medial canthal region and conjunctival caruncle, the medial transitional zone between skin, and medial bulbar conjunctiva."[10] A ten point scale was developed with zero signifying normal for children without Down syndrome and to a maximum of ten signifying an appearance consistent with the more pronounced presentation of this feature. For example, a lack of any noticeable (or completely flat) nose bridge would receive a score of, [10] whereas a completely normal appearing nose bridge would receive a score of zero.

Some data was excluded if it was unclear from the photographs. Regarding the nose bridge, those photographs of patients wearing glasses were normally excluded; for epicanthal fold those photographs (mainly of infants) whose eyes were closed or those whose ancestry pre-disposed them for an epicanthal fold were normally excluded.

Warner made all of his non-archived files available. Files were randomly selected using a random number table. Files were accepted if they had initial and final age, combined with initial and final photographs with adequately discernible features. As this investigation was limited to children, files for patients with ages above 16.0 were excluded. Of the selected files, 85 met the criteria for reviewing facial swelling, 82 for nose bridge, and 81 for epicanthal fold. Approximately 1,500 non-archived records were es-

timated to be available which met these criteria. This investigation was pre-approved by an independent review board.

Results

85 of the records selected were analyzed to discern facial swelling/edema as shown in Table 1.(below)

65 of the 85 had improved facial swelling improvement. The data was analyzed utilizing regression analysis. Gender differences were statistically significant as males improved much more than females (57.6% improvement vs. 28.8% improvement). The average (mean) age at the initial appointment was 2.2 years whereas the average age at the final appointment was 5.2 years. 82 of the records selected were analyzed to discern the formation of a normal nose bridge as shown in Table 2. (below)

62 of the 82 had improved nose bridge appearance. The data was analyzed utilizing regression analysis. Unlike facial swelling, the gender differences were not statistically significant. The average (mean) age at the initial appointment was 2.2 years whereas the average age at the final appointment was 5.1 years. 81 of the records selected were analyzed to discern the amount of epicanthal eye fold as shown in Table 3 (below).

Table 1. Facial swelling (excessive = 10).

Gender	N	Attribute	Initial Mean on 10 Point Scale	Final Mean on 10 Point Scale	Percent Improvement
Female	39	Facial Swelling	5.9	4.2	28.8%
Male	46	Facial Swelling	6.6	2.8	57.6%
Total	85	Facial Swelling	6.3	3.4	46.0%

Table 2. Nose Bridge (lack of =10).

Gender	N	Attribute	Initial Mean on 10 Point Scale	Final Mean on 10 Point Scale	Percent Improvemen
Female	37	Nose Bridge	7.8	5.1	34.6%
Male	45	Nose Bridge	7.5	5.2	30.7%
Total	82	Nose Bridge	7.6	5.1	32.9%

Table 3. Epicanthal Fold (highly discernible =10)

Gender	N	Attribute	Initial Mean on 10 Point Scale	Final Mean on 10 Point Scale	Percent Improvement
Female	38	Epicanthal Fold	5.4	3.8	29.6%
Male	43	Epicanthal Fold	6.1	4.0	34.4%
Total	81	Epicanthal Fold	5.8	3.9	32.8%

56 of 81 had improvement in the epicanthal fold appearance. The total data was analyzed utilizing regression analysis. Gender differences were not statistically significant. The average (mean) age at the initial appointment was 2.3 years whereas the average age at the final appointment was 5.2 years.

Discussion

The advocacy of an interdisciplinary approach for Down syndrome patients predates Dr. Warner's involvement.[11] The fact that children undergoing the Warner protocol showed significant improvement in appearance seems to suggest that interventions such as those used by Warner are helpful when begun at an early age. Others using similar formulas have also claimed that nutrition can improve facial features. Turkel, probably the best known pioneer of using nutrition for those with Down syndrome, includes many before and after photographs in his book, Medical Treatment of Down Syndrome and Genetic Disorder, to demonstrate the improvement [8]. Turkel's work, as well as this investigation of Warner House, suggest that appearance can be improved. This is not to say that children with Down syndrome who follow the Warner protocol will no longer be identifiable as having Down syndrome on the basis of appearance only, but that they will tend to develop a more normal appearance.

There have been case reports that other nutrients can also affect appearance. Two years after taking a supplement containing essential monosaccharides, Michelle Desrochers showed facial improvement in all the areas that this study covered.[12] There is also a case report that indicated that injections of dimethyl sulfoxide (DMSO), gamma amino butyric acid (GABA), gamma-aminobeta-hydroxybutric acid (GABOB), and acetylcholine helped improve appearance for another child with Down syndrome.[13]

Triplication of the 21st chromosome causes metabolic disturbances which lead to an accumulation of various metabolic precursors and a deficiency of certain end products—this is one of the basic reasons why nutritional interventions make scientific sense for persons with Down syndrome [8,14,15] It has been claimed that it may only be a particular region of the 21st chromosome (band 21q22) that causes the features which are associated with Down syndrome .[16] Beyond that, some believe that it is the high level of free radicals and imbalance of antioxidants that lead to the distinctive changes in appearance associated with Down syndrome.[14] Superoxide dismutase and alpha and beta-interferon levels are elevated for those with Down syndrome.[2,17] It has been hypothesized that supplemental vitamin E may reduce superoxide dismutase-generated oxidative damage in Down syndrome patients;[18] it has also been speculated that supplementation with other antioxidant nutrients can do the same thing.[15,19] Levels of alanine, cysteine, isoleucine, lysine, phenylalanine, and threonine seem to be elevated, yet tyrosine, folate, manganese, iron, thiamin, vitamin B_{12}, vitamin C, vitamin E, and selenium levels appear to be depressed (additional nutrients have also been implicated).[8,20-23] Some minerals, such as calcium and magnesium, seem to be higher than non-Down's patients in some areas of the body, yet lower in others areas.[8,20] It has been speculated that the alteration of the conjunctival epithelium in patients with Down syndrome may be due to altered metabolism of vitamin A.[24] Disorders of vitamin D metabolism have also been speculated for Down's patients,[8,25] and since vitamin D does affect bone development, it probably plays a role in appearance. It simply makes sense to this researcher that if nutrition is abnormal, that appearance can be affected, and that appropriate supplementation can help and should be considered. Furthermore, it has been shown that people with

Down syndrome who display the more pronounced facial features are simply not viewed as well by society.[26]

Down's patients are more susceptible to certain ophthalmological problems than the general public (most notably strabismus) which leads to distortion of vision.[10] Early ophthamological interventions, such as provided by Warner House, could be expected to lead to improved vision. It does not seem likely, though, that this would affect nose bridge or epicanthal folds. It is of further interest to note that a study of an ophthalmological nature concluded "that between the ages of 7 and 14 years, facial characteristics of children with Down syndrome do not change with age".[27] For children whose first and last photograph were between 7 and 14 years of age, a subset of Warner's records suggest that facial features did change for the positive with 84.4%, 6.3%, and 63.5% improvement for facial swelling, nose bridge, and epicanthal fold respectively—the low improvement for nose bridge (6.3%) suggests this area improves little during this stage of development.

Physical therapy, such as recommended by Warner House, could be expected to improve muscle tone. Some reports suggest that physical therapy could have some effects on appearance and intelligence of those with Down syndrome, especially when used as part of a multidisciplinary approach.[28-29] One study involving the Castillo Morales method concluded that the symptoms "tongue mostly protruding over the lips" and "mouth wide open" were reduced,[30] which are not determinable features from examining photographs at Warner's clinic. Some of the osteopathic literature suggests that osteopathic manipulation can be helpful to normalize facial features for children with Down syndrome.[31]

Conclusion

Although this investigation was preliminary, it appears that there is some efficacy in the Warner protocol regarding facial features. As the Warner protocol combines nutrition with physical therapy, medicine, and ophthalmology, it is not possible to statistically segregate the impact of any one of those interventions. It is possible that all of the interventions may work synergistically to improve facial appearance or that one or more interventions on its own has the most (or the entire) effect. Nutrition probably has the greatest effect on appearance, with physical therapy probably having the next largest impact. A prospective study would be needed in order to assess the possible impact of any single intervention. This investigator believes that the data in this paper favorably support the need for such a study.

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