

Health Care Use by Children Diagnosed as Having Developmental Delay

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Background: Although children with developmental delay are known to have increased health care use, it is unclear what proportion of that health care use is related to associated chronic health conditions.

Objectives: To assess the prevalence of isolated developmental delay and to determine the role of developmental delay in health care use controlling for chronic health conditions.

Design: Retrospective cohort study using Washington State Medicaid claims records from November 1, 1990, to December 31, 1997, an administrative data set that contains both *International Classification of Diseases, Ninth Revision, Clinical Modification* codes and billed services.

Patients and Setting: Children born between November 1, 1990, and December 31, 1992, diagnosed as having developmental delay before the age of 5 years, enrolled in Medicaid within 1 month of birth, and continuously enrolled for at least 12 months. Four control sub-

jects per case were matched on date of birth and duration of continuous enrollment in Medicaid.

Main Outcome Measures: Visits to physicians, emergency departments, other practitioners, or hospitals by year of life.

Results: One thousand two hundred forty-two children having developmental delay and 5370 children without developmental delay were included. One percent of those who met study criteria had developmental delay without chronic health conditions and 30% of the children with developmental delay had no associated chronic health conditions. Boys were 1.6 times as likely to have a diagnosis of developmental delay. Developmental delay was independently associated with increased health care use by all 4 measures used.

Conclusion: Developmental delay increases health care use apart from associated chronic health conditions.

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ESTIMATED TO constitute between 2% and 10% of the pediatric population, children with developmental delay have been shown to use more health care than children without developmental delay.¹⁻⁵ However, developmental delay is associated with chronic health conditions that also increase health care use.⁶ The prevalence of isolated developmental delay and the role it plays in the use of health services, apart from comorbid chronic health conditions, is unknown. This study was designed to determine the prevalence of isolated developmental delay and to describe the role that developmental delay plays in health care use in the first 5 years of life controlling for chronic health conditions.

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RESULTS

A total of 126 671 children with a birth date between November 1, 1990, and December 31, 1992, were enrolled in Washington State Medicaid. Of these, 38 244 (30.2%) were enrolled within 1 month of birth and continuously for at least 12 months. Of these, 1242 (3.2%) were identified as having developmental delay. A total of 5370 children were randomly selected as controls.

The demographic characteristics of the study population are shown in **Table 1**. Children having a diagnosis of developmental delay were more likely to be male, less likely to have race recorded as Hispanic or other, and more likely to have race recorded as unknown. Eighty-one percent of the study children were en-

PATIENTS AND METHODS

PATIENTS

We performed a retrospective longitudinal cohort study using Washington State Medicaid claims data from November 1, 1990, to December 31, 1997, that contain both encounter data and *International Classification of Diseases, Ninth Revision, Clinical Modification* coding. Eligible children were born between November 1, 1990, and December 31, 1992, and were diagnosed as having developmental delay (*International Classification of Diseases, Ninth Revision, Clinical Modification* codes 315, 317, 318, and 319). To ensure complete information on health care use, we included only those children who were enrolled in Medicaid within 1 month of birth and who remained continuously enrolled for at least 12 months thereafter, as determined by review of the Medicaid eligibility file. The diagnosis of developmental delay had to occur prior to the first break in Medicaid enrollment and before the child was 5 years old. Claims submitted before the first lapse in enrollment, or until the child was 5 years old, whichever came first, were included in this analysis.

We maximized study power by randomly selecting 4 control subjects per case, matched within 1 month of the date of birth and by duration of continuous enrollment in Medicaid. Children selected as controls could not have had a diagnosis of developmental delay in the Medicaid claims data prior to their fifth birthday, regardless of any lapse in enrollment.

CHRONIC HEALTH CONDITIONS

To assess the presence of chronic health conditions, *International Classification of Diseases, Ninth Revision, Clinical Modification* diagnoses were grouped by body system. Included conditions were those that would be expected to affect a child's physical well-being for 6 months or longer and necessitate medical and/or surgical intervention. A list of conditions is available from us on request. We included all diagnoses that occurred in the claims data during the first period of continuous enrollment, or until the child was 5 years old, whichever came first. Children who had one or more diagnoses within a single body system were considered to have 1 chronic health condition. To maximize sensitivity and to ensure a representative sample of children without chronic health conditions, a diagnosis need only be present once to classify a child as having that condition.

HEALTH CARE USE

Health care use was the outcome of interest and was assessed based on the type of health care provider submitting the claim to Medicaid. Health care providers were grouped as follows: physician (includes outpatient clinic),

hospital, emergency department (ED), and other practitioner (includes physical therapist, occupational therapist, speech therapist, audiologist, and services provided by schools). We assessed the number of visits to a physician, other practitioner, ED, and hospitalizations based on claims submitted to Medicaid. If 2 different health care providers submitted a claim for the same child on the same day, 2 visits were counted. Claims for visits by a physician or other practitioner that occurred during the course of a hospitalization were counted as part of the hospitalization and, thus, were excluded from the calculations of use for physician or other practitioner.

We adjusted utilization measures for the total person-time contributed by each child, since all children were not enrolled for the full 5 years, including the total months of continuous enrollment from birth to the first break in enrollment or until the child was 5 years old, whichever was less, in the denominator. Visits to a physician or outpatient clinic, ED, and other practitioners are reported as the mean number per child by year of life. Hospitalizations are reported as the mean number per 100 children by year of life. Because of incomplete data, hospitalizations in the first year of life include only those that occurred after the birth hospitalization. In Washington state, an infant's hospital care at delivery for an uncomplicated birth is covered by the mother's Medicaid number, so this hospitalization is not recorded on the infant's Medicaid claims.

ANALYSIS

Analyses of use were stratified by 4 groups: (1) children who had developmental delay and no chronic health conditions; (2) children who had no developmental delay and no chronic health conditions; (3) children who had developmental delay with 1 or more chronic health conditions; and (4) children who had no developmental delay, but who had 1 or more chronic health conditions. Given the skewed distribution of visits per child, we compared the mean values using the non-parametric Kruskal-Wallis test.⁷ A prevalence odds ratio (OR) was used to compare categorical variables; the Mantel-Haenszel OR was used to provide a summary prevalence OR for chronic conditions stratified by sex.⁸ We used the Cornfield approximation for the 95% confidence interval (CI).⁹

We developed a series of regression models to assess the independent association of developmental delay on our utilization measures. Because of the skewness of the distribution of these measures, we used negative binomial regression to calculate adjusted incident rate ratios (IRRs).¹⁰ The dependent variable was the number of visits by each type of health care provider during the child's first 5 years of life. The independent variable of interest was developmental delay (0, none; 1, present). Sex (0, female; 1, male), race (white race as reference), and the type of chronic health condition (0, not present; 1, present) were included in the model to adjust for confounding.

rolled continuously for 4 to 5 years (Table 1). The mean (SD) age of the first diagnosis of developmental delay was 33.7 (12.6) months, with a median of 33 months.

CHRONIC HEALTH CONDITIONS

Table 2 summarizes the frequency of chronic health conditions among children with and without developmen-

tal delay. Children with developmental delay were twice as likely to have 1 or more chronic health conditions. Of the children with developmental delay, 391 (32%) had isolated developmental delay. This is 1% of the 38244 children who were enrolled in Medicaid at birth and continuously for at least 12 months.

One third of the children with developmental delay had only 1 chronic health condition in addition to

Table 1. Demographic Characteristics of Study Population

Variable	No. (%) of Children With Developmental Delay (n = 1242)	No. (%) of Children Without Developmental Delay (n = 5370)	Prevalence Odds Ratio* (95% Confidence Interval)
Sex			
Male	786 (63.3)	2751 (51.2)	1.64 (1.44-1.87)
Female	456 (36.7)	2619 (48.8)	
Race or ethnicity			
White	726 (58.4)	3294 (61.5)	0.89 (0.78-1.01)
Black	101 (8.1)	452 (8.4)	0.96 (0.76-1.21)
Hispanic	163 (13.1)	831 (15.5)	0.83 (0.69-0.99)
Other	109 (8.8)	654 (12.2)	0.69 (0.56-0.86)
Unknown	143 (11.5)	139 (2.6)	4.90 (3.82-6.28)
Continuous enrollment, No. of y†			
1	11 (0.9)	37 (0.7)	...
2-3	252 (20.3)	980 (18.2)	...
4-5	979 (78.8)	4353 (81.1)	...

*Comparing children with developmental delay with those without developmental delay.

†Children with developmental delay and without developmental delay were matched within 1 month of duration of continuous enrollment; thus, prevalence odds ratio is not valid as indicated by the ellipses.

developmental delay (Table 2). Thirty-seven percent had 2 or more chronic health conditions in addition to developmental delay. Among the children who did not have a diagnosis of developmental delay, there were twice as many children with no chronic health conditions compared with those with developmental delay, and only 9% had 2 or more chronic health conditions (Table 2).

Children with developmental delay were more likely to have every chronic health condition that we examined. Compared with children without developmental delay and controlling for sex, children with developmental delay were more than 9 times as likely to have a central nervous system condition; nearly 9 times as likely to have an ear, nose, and throat condition; and more than 5 times as likely to have a gastrointestinal tract disorder. Respiratory and neoplastic conditions had the lowest association with developmental delay. Children with developmental delay were 1½ to 2 times as likely to have these conditions compared with children without developmental delay.

HEALTH CARE USE

Health care use by year of life is shown in the **Figure**. Children with developmental delay who also had 1 or more chronic health conditions had the highest use in all of the categories measured. The mean number of physician visits, ED visits, and hospitalizations per child decreased as the age of the child increased. Visits to other practitioners increased as the age of the child increased. Similar patterns in use were observed when the data were stratified by sex and race.

PHYSICIAN VISITS

Children with isolated developmental delay had more visits to a physician in the first year of life compared with

Table 2. Number of Chronic Health Conditions Among Children Who Have and Who Do Not Have a Diagnosis of Developmental Delay

No. of Chronic Health Conditions	No. (%) of Children With Developmental Delay (n = 1242)	No. (%) of Children Without Developmental Delay (n = 5370)	Prevalence Odds Ratio* (95% Confidence Interval)
0	391 (31.5)	3360 (62.6)	0.27 (0.24-0.31)
1	402 (32.4)	1550 (28.9)	1.18 (1.03-1.35)
2	244 (19.7)	378 (7.0)	3.23 (2.70-3.86)
≥3	205 (16.5)	82 (1.5)	12.75 (9.71-16.76)

*Comparing prevalence of characteristic among children with developmental delay with the prevalence among children without developmental delay.

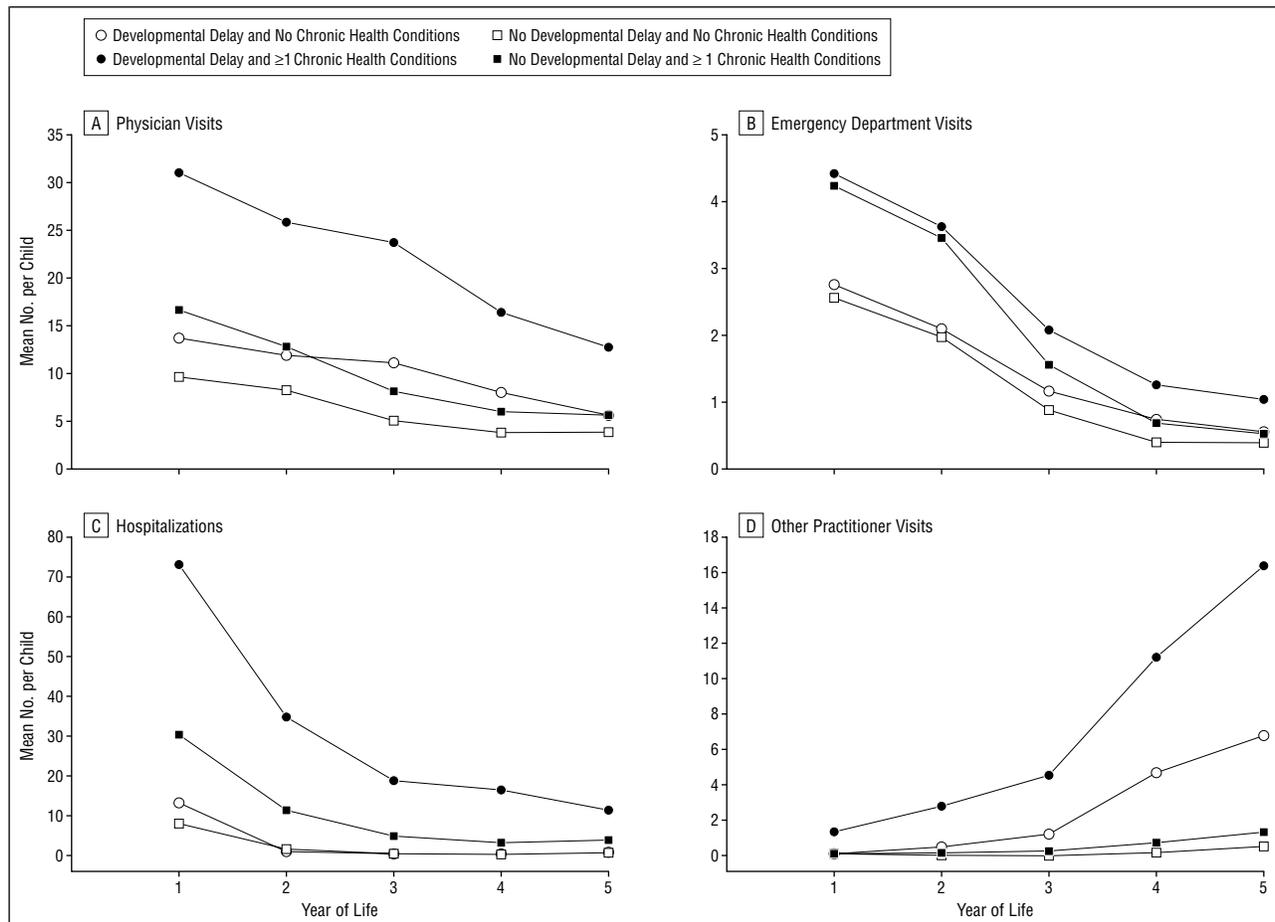
children who had no developmental delay and no chronic health conditions ($P < .001$) (Figure A), but fewer than those children who had chronic health conditions but no developmental delay ($P < .001$). By the fifth year of life, the number of physician visits was similar among children with isolated developmental delay and those without developmental delay who had 1 or more chronic health conditions, and greater than that for children without developmental delay and without chronic health conditions ($P < .001$). The regression model estimated that children with developmental delay have 1½ times as many physician visits in the first 5 years of life compared with children without developmental delay (IRR, 1.55; 95% CI, 1.49-1.63).

ED VISITS

In the first 3 years of life, children with chronic health conditions had a greater mean number of visits to the ED compared with children without chronic health conditions ($P < .001$) (Figure B). Although the mean number of ED visits per child declined in all groups, children with developmental delay and chronic health conditions continued to have a greater mean number of ED visits per child in the fourth and fifth years of life compared with the other 3 groups ($P < .001$). In the fifth year of life, children with developmental delay and chronic health conditions had a mean of 1 visit per child to the ED, while the other groups had fewer than 0.5 visits per child. Children with developmental delay had a slight increase in ED use in the first 5 years compared with children without developmental delay (IRR, 1.09; 95% CI, 1.00-1.18).

HOSPITALIZATIONS

The number of hospitalizations per 100 children was greatest for children with developmental delay and chronic health conditions, followed by children with chronic health conditions without developmental delay (Figure C). Children without chronic health conditions had few hospitalizations, a mean of 1 or fewer per 100 children per year of life in the second through fifth years of life. After the second year of life, only children with developmental delay and chronic health conditions had a higher mean number of hospitalizations per 100 children com-



Health care use by type of health care provider among children with and without developmental delay and chronic health conditions during the first 5 years of life.

pared with the other 3 groups ($P < .01$). Developmental delay was independently associated with an increase in hospitalizations in the first 5 years of life (IRR, 1.76; 95% CI, 1.42-2.18).

OTHER PRACTITIONER VISITS

The mean number of visits per child per year to other practitioners was greatest for children with developmental delay (Figure D). Children with developmental delay and chronic health conditions had the greatest mean number of visits to other practitioners in all years ($P < .001$). Beginning in the second year of life, children with developmental delay and no chronic health conditions had a greater mean number of visits to other practitioners compared with children without developmental delay ($P < .002$). Compared with children without developmental delay, those with developmental delay had more than 10 times the number of visits to other practitioners (IRR, 10.49; 95% CI, 8.08-13.63).

COMMENT

Our study demonstrates that 1% of the children in this cohort had isolated developmental delay, nearly one third of those diagnosed as having developmental delay. Although other studies have estimated the prevalence of young children with developmental delay,¹⁻⁴ none, to our

knowledge, have assessed the prevalence of isolated developmental delay.

Children diagnosed as having developmental delay were more likely to be male. This may reflect a true difference in the prevalence of developmental delay among boys. However, it may be confounded by a parental propensity to seek care for boys or health care provider willingness to diagnose developmental delay in boys. Although we did not identify studies examining sex differences among young children diagnosed as having developmental delay, several studies have examined sex differences among children with mental retardation, finding that use of services for mental retardation is more common in boys.¹¹⁻¹³ However, sex differences have not been noted if standardized testing alone is used to identify children with mental retardation.¹² These differences may be attributed to behavioral and adaptive differences between boys and girls. Further studies are needed to determine if these differences seen with mental retardation hold for children diagnosed as having developmental delay.

Although earlier studies have shown an association between increased health care use and the presence of developmental delay,¹ they have not clarified the role that developmental delay itself plays in that use apart from chronic health conditions. Our multivariate analysis shows that developmental delay is associated with increased health care use in the first 5 years of life in the 4 areas

What This Study Adds

Although children with developmental delay are known to have increased health care use, it is unclear what role developmental delay plays in that use apart from associated chronic health conditions. Also, the prevalence of developmental delay without the presence of chronic health conditions is unknown.

Developmental delay without chronic health conditions affects 1% of this Medicaid population, and 30% of the children with developmental delay have no associated chronic health conditions. Developmental delay is associated with significant health care use, in particular physician visits and services by other health care providers. Boys are more likely to be diagnosed as having developmental delay.

that we assessed. Although we did not specifically assess the diagnoses associated with the increased number of visits, the reasons for more frequent physician visits and hospitalizations among children with developmental delay may include monitoring a child's development, as well as establishing the diagnosis of developmental delay and assessing possible causes. The increasing frequency of visits to other practitioners are likely secondary to evaluation and intervention services. Children with developmental delay benefit from early intervention with respect to enhanced development and improved family functioning.¹⁴⁻¹⁷ The presence of developmental delay may make management of these children more challenging for health care providers and families, necessitating greater health care use. We were unable to address that issue in this study.

The number of visits to other health care providers increases dramatically after 3 years of age among children with developmental delay. The reason for this increase may include that the mean age of diagnosis of developmental delay was almost 34 months, so many children begin receiving services in their third year of life. Those receiving services before 3 years of age may continue to receive services after 3 years of age if they continue to meet eligibility criteria. Additionally, as children get older, there are greater expectations for what they should be able to do, and new areas of need may manifest as the children begin to enter a learning environment, prompting referral to more or different services.¹⁸

The rates of health care use in our study are similar to those reported in other studies.^{1,19} In one study, children younger than 6 years receiving Medicaid or who were uninsured had a mean hospitalization rate of 15 per 100 children and an ED visit rate of 0.5 per child in the year prior to the study.¹⁹ Among children with isolated developmental delay and those without developmental delay, the rates of hospitalizations were lower than found in this study, while the rate of ED visits was greater in the first 3 years of life. This was a cross-sectional study where children were selected based on insurance status. By selecting children because they had a diagnosis of developmental delay and including only those who remained continuously enrolled for 12 months or longer,

we overselected children with chronic health conditions and, thus, greater health care use.

In the National Health Interview Survey, Child Health Supplement (NHIS-CH), children aged 0 to 17 years with no developmental disabilities had a mean of 2.8 visits to physicians in the year prior to the survey, and those children with developmental disabilities had a mean of 6.1 visits to physicians in the year prior.¹ In this same study, children without disabilities had a mean of 4.0 hospitalizations per 100 children, and those with disabilities had a mean of 17.8 hospitalizations per 100 children. Although the mean number of physician visits and hospitalizations in our study was higher, the NHIS-CH reported a mean across a much broader age range. Other factors that may account for the differences seen in the NHIS-CH and our study were that the NHIS-CH was based on parental report, while our numbers are based on claims submitted. Also the NHIS-CH included a nationwide sample of children, not just those receiving Medicaid.

There are several limitations to this study. First, because it is based on claims data, the classification of children with and without developmental delay and with and without chronic health conditions is only as good as the diagnoses coded in these data. Claims data are likely to underestimate the presence of developmental delay and would bias our results against finding a difference between children with and without developmental delay. However, we found a 3.2% prevalence of developmental delay among young children continuously enrolled for at least 1 year from birth, which is consistent with previously published estimates of developmental delay.^{1,4} Second, we may have misclassified children as not having developmental delay when, in fact, they were developmentally delayed. The effect of this type of misclassification is likely to be very small since the prevalence of developmental delay is low. Third, we may have missed some use if care was paid for by another source. Children receiving Supplemental Security Income may have had private insurance in addition to Medicaid and we were unable to capture use paid for by other sources. This would lead to an underestimate of use in this study. The Individuals With Disabilities Education Act Part H (now Part C), the special education law covering 0- to 3-year-olds, and the public schools provide developmental services that would not necessarily be reflected in the Medicaid data; however, these sources often do submit claims to Medicaid. We sought to minimize problems in ascertainment by including only those children who were continuously enrolled from birth and only examining the first period of continuous enrollment in Medicaid. Lastly, this study only assessed use among a continuously enrolled Medicaid population. These results may not be generalizable to other populations.

Despite these limitations, this study is an important first step in estimating the prevalence of isolated developmental delay and understanding the role of developmental delay in young children's health care use. Although children with developmental delay and chronic health conditions have markedly increased use, it seems as if chronic health conditions, rather than developmental delay are responsible for most of that increase; however, developmental delay may complicate the manage-

ment of these children. Further studies are needed to determine if these same patterns of health care use are seen in other non-Medicaid populations and to assess the role of developmental delay in altering the management of children with 1 or more chronic health conditions.

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REFERENCES

1. Boyle CA, Decoufle P, Yeargin-Allsopp M. Prevalence and health impact of developmental disabilities in US children. *Pediatrics*. 1994;93:399-403.
2. Drillien CM, Pickering RM, Drummond MB. Predictive value of screening for different areas of development. *Dev Med Child Neurol*. 1988;30:294-305.
3. Dworkin PH. British and American recommendations for developmental monitoring: the role of surveillance. *Pediatrics*. 1989;84:1000-1010.
4. Kirby RS, Brewster MA, Canino CU, Pavin M. Early childhood surveillance of developmental disorders by a birth defects surveillance system: methods, prevalence comparisons, and mortality patterns. *J Dev Behav Pediatr*. 1995;16:318-326.
5. Disabilities among children aged ≤ 17 years—United States, 1991-1992. *MMWR Morb Mortal Wkly Rep*. 1995;44:609-613.
6. Coiro MJ, Zill N, Bloom B. Health of our nation's children. *Vital Health Stat 10*. 1994;191:1-61.
7. Kruskal W, Wallis W. Use of ranks in one-criterion variance analysis. *J Am Stat Assoc*. 1952;47:583-621.
8. Rothman K, Greenland S. *Modern Epidemiology*. 2nd ed. Philadelphia, Pa: Lippincott-Raven; 1998.
9. Cornfield J. A statistical problem arising from retrospective studies. In: Neyman J, ed. *Proceedings of the Third Berkeley Symposium on Mathematical Statistics and Probability*. Vol 4. Berkeley: University of California Press; 1956:135-148.
10. Rodriguez G. An improvement to Poisson. *Stata Technical Bull*. 1993;11:11-14.
11. Katusic SK, Colligan RC, Beard C, et al. Mental retardation in a birth cohort, 1976-1980, Rochester, Minnesota. *Am J Ment Ret*. 1995;100:335-344.
12. Richardson SA, Katz M, Koller H. Sex differences in number of children administratively classified as mildly mentally retarded: an epidemiologic review. *Am J Ment Defic*. 1986;91:250-256.
13. Murphy C, Yeargin-Allsopp M, Decoufle P, Drews CD. The administrative prevalence of mental retardation in 10-year-old children in metropolitan Atlanta, 1985 through 1987. *Am J Pub Health*. 1995;85:319-323.
14. Guralnick MJ. The next decade of research on the effectiveness of early intervention [review]. *Except Child*. 1991;58:174-183.
15. Casto G, Mastropieri MA. The efficacy of early intervention programs: a meta-analysis [review]. *Except Child*. 1986;52:417-424.
16. Shonkoff JP, Hauser-Cram P. Early intervention for disabled infants and their families: a quantitative analysis [review]. *Pediatrics*. 1987;80:650-658.
17. Shonkoff JP, Hauser-Cram P, Frauss MW, Upshur CC. Development of infants with disabilities and their families: implications for theory and service delivery [review]. *Monogr Soc Res Child Dev*. 1992;57:v-vii, 1-153.
18. Newacheck PW, Stoddard JJ. Prevalence and impact of multiple childhood chronic illnesses. *J Pediatr*. 1994;124:40-48.
19. Polivka BJ, Nickel JT, Salsberry PJ, Kuthy R, Shapiro N, Slack C. Hospital and emergency department use by young low-income children. *Nurs Res*. 2000;49:253-261.

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ARCHIVES OF OPHTHALMOLOGY

The Clinical Profile of Moderate Amblyopia in Children Younger Than 7 Years

The Pediatric Eye Disease Investigator Group

Objective: To describe the demographic and clinical characteristics of a cohort of children with moderate amblyopia participating in the Amblyopia Treatment Study 1, a randomized trial comparing atropine and patching.

Methods: The children enrolled were younger than age 7 years and had strabismic, anisometropic, or combined strabismic and anisometropic amblyopia. Visual acuity, measured with a standardized testing protocol using single-surround HOTV optotypes, was 20/40 to 20/100 in the amblyopic eye, with an intereye acuity difference of 3 or more logMAR lines. There were 419 children enrolled, 409 of whom met these criteria and were included in the analyses.

Results: The mean age of the 409 children was 5.3 years. The cause of the amblyopia was strabismus in 38%, anisometropia in 37%, and both strabismus and anisometropia in 24%. The mean visual acuity of the amblyopic eyes (approximately 20/60) was similar among the strabismic, anisometropic, and combined groups ($P=.24$), but visual acuity of the sound eyes was worse in the strabismic group compared with the anisometropic group ($P<.001$). For the patients randomized to the patching group, 43% were initially treated for 6 hours per day, whereas 17% underwent full-time patching. Patients with poorer visual acuity in the amblyopic eye were prescribed more hours of patching than patients with better acuity ($P=.003$).

Conclusions: In the Amblyopia Treatment Study 1, there were nearly equal proportions of patients with strabismic and anisometropic amblyopia. A similar level of visual impairment was found irrespective of the cause of amblyopia. There was considerable variation in treatment practices with regard to the number of hours of initial patching prescribed. (2002;120:288-293)

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