Parent and Physician Response to Children's Cholesterol Values of 200 mg/dL or Greater: The Child and Adolescent Trial for Cardiovascular Health Experiment

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ABSTRACT. *Objective.* **To determine parental actions and concerns and physician responses to parental notification that a child's cholesterol value was 200 mg/dL or greater, a value recommended by the National Cholesterol Education Program to warrant physician follow-up and evaluation.**

Methodology. **A telephone survey of parents (n = 784) and physicians (n = 117) was carried out after parental notification of a total blood cholesterol value obtained as part of measurement done while participating in the Child and Adolescent Trial for Cardiovascular Health in 96 schools located in California, Louisiana, Minnesota, and Texas.**

Results. **Only 20% of parents contacted physicians. Factors associated with this action included whether the parent was notified once or twice, the level of the cholesterol, previous cholesterol testing in the parent, and medical insurance that covered the visit. Family history of cardiovascular disease, when other factors were considered, did not increase the likelihood that a physician contact would be made. After contact with the physician, 59% of physicians reported evaluating children for cholesterol; about half reported repeating the cholesterol determination.**

Conclusion. **Parental knowledge of a child's cholesterol value of 200 mg/dL or greater did not result in substantially further seeking of health care.** ***Pediatrics*** **1997;99(5). URL: http://www.pediatrics.org/cgi/content/full/99/5/e5;** ***children, elevated cholesterol, parental response, physician response.***

ABBREVIATIONS. NCEP, National Cholesterol Education Program; CATCH, Child and Adolescent Trial for Cardiovascular Health.

Screening children for blood cholesterol levels is currently recommended for those with positive family histories of premature cardiovascular disease.[1] Wider screening has not received much support. Recent literature suggests that childhood levels of cholesterol cannot be expected to decrease greatly with only dietary measures, and that untested longer adverse effects might ensue if lipid-lowering agents are used.[2,3] Opponents of wide screening of children for blood cholesterol have pointed out that concern over "elevated" levels might create unnecessary and unproductive anxiety in parents and children. Proponents of ascertaining childhood levels of cholesterol point to the relatively strong "tracking" of cholesterol over time and the failure of family history to detect elevated cholesterol levels in children or to elicit information on cholesterol levels in family members.[4–6] The relationship of adult cardiovascular disease to cholesterol levels, as well as the presence of early atherosclerotic lesions in blood vessels of youth being correlated with childhood levels of low-density lipoprotein cholesterol,[7,8] have also been cited as rationale for knowing children's cholesterol levels.

The response of parents or physicians in practice to the recent National Cholesterol Education Program (NCEP)[1] recommendations is largely unknown. Previous surveys have indicated that a significant proportion of pediatricians were screening some children for cholesterol.[9,10] Until now, little information was available on parental actions and concerns and physician responses to parental notification that a child's cholesterol value was 200 mg/dL or greater, a value recommended by the NCEP to warrant physician follow-up and evaluation.[1]

The occurrence of a large, four-region (San Diego, CA; New Orleans, LA; Minneapolis, MN; and Austin, TX) trial of a school-based intervention provided an opportunity to assess the impact on parents, children, and physicians of the knowledge that a child had a total blood cholesterol value found to be elevated (200 mg/dL or greater, according to NCEP guidelines). The total blood cholesterol level measurements for this study were obtained as part of participation in a health trial rather than as a result of a screening procedure in a physician's office regarding cholesterol level. This would somewhat mimic the conditions that might pertain to a larger screening situation, however, in that after detection of an elevated value, further confirmation and follow-up are suggested.

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Study questions addressed by this research include reported concerns or worries subsequent to the notification of an elevated level and any actions taken by the family. Actions taken could include consulting a physician about the test result and/or initiating dietary or other health habit changes. We also assessed the effects of geography, finances for medical care, ethnicity, gender, presence or absence of family history of heart disease, and study group assignment on actions taken by the parents. In addition, we assessed physician responses to consultation for this issue.

METHODS

Overview of Main Child and Adolescent Trial for Cardiovascular Health Trial

The primary goal of Child and Adolescent Trial for Cardiovascular Health (CATCH) was to assess the effects and safety of classroom, family involvement, and school environmental interventions on school policies and practices (school nutrition, physical education programs, and tobacco control policies) on promoting healthy eating, physical activity, and tobacco nonuse behaviors in the children attending the schools.[11] The main results of CATCH are reported elsewhere.[12] All subjects participated voluntarily and under protocols approved by human subjects review boards in all the academic institutions involved. Numerous school level and behavioral measures were collected yearly. Total blood cholesterol and other physiologic measures such as height, weight, blood pressure, and skin fold thickness were measured at the beginning of the third grade (fall 1991) and in the spring at the end of fifth grade (spring 1994). The CATCH cohort (N = 5106) constituted all children who were measured at baseline and for whom a cholesterol level was obtained. The baseline results have been reported previously.[13]

All CATCH cohort children's parents were mailed a letter after each assessment, at baseline, and at follow-up, which gave the results of the child's height, weight, average systolic blood pressure, average diastolic blood pressure, and total blood cholesterol value. The following paragraph was included in every letter; the intent of the investigators was to emphasize the recommendation, but not to cause undue alarm:

> Total blood cholesterol: 205 mg/dL. Current recommendations are that blood cholesterol be below 200 mg/dL. However, a single measurement is not adequate to make a diagnosis of high blood cholesterol. Thus, if your child's value is above 200, we recommend that you see your own physician for further testing and advice.

The letter was signed by the principal investigator at each study site, and a phone contact for the CATCH site investigator was given if a parent had questions. Lists of all children and their values were given to each CATCH site principal investigator for handy reference should a parent or physician call. Principal investigators reported few (generally less than 10) calls at each site. The school nurse, if present in a CATCH study school, was also given a list to follow up with the parents.

Measurement and Definitions

Total blood cholesterol levels were quantified by enzymatic methods on a Gilford Impact 400 computer-directed analyzer, using a modified Lipid Research Clinic (LRC) protocol by the Division of Nutrition and Metabolism, Miriam Hospital, Brown University (Providence, RI), under the direction of Peter Herbert, MD.[14] Family history of heart disease was defined as the presence of heart disease in one or more close relatives, including parents, their siblings, and grandparents of the index child, as reported by a parent.

Between 3 months and 6 months after the final fifth-grade measurement of the cohort, a telephone survey was conducted by the University of Minnesota Phone Survey Unit. The period between notification of a parent and the telephone survey could range between 3 months and 3 years, depending on which measurement (third or fifth grade) was pertinent. Some parents had children with levels of 200 mg/dL or greater at both third and fifth grades and would have received two notices. Parents were initially contacted; their physicians were contacted after parental permission had been granted. Interviewers were trained and supervised by the Division of Epidemiology, University of Minnesota. The content for the 30- to 40-minute interview included: parental recall of and action taken regarding notification at either the third or fifth grade of a child's cholesterol level being 200 mg/dL or greater; demographic data; perceived levels of concern (parents and child); cholesterol testing of parents; recent changes in diet and exercise habits; and medical insurance information. Study group assignment was already in the database. Pretesting assured respondent feasibility and reliability of survey instruments. Interviews were completed using a computer-assisted telephone interviewing software package available from the University of California (Berkeley, CA). The primary reason for not completing an interview was the inability to locate and reach the family after no less than 3 but up to 10 attempts were made.

Statistical Methods

Frequency distributions and cross-tabulations were used to describe the study population and general response patterns. The main outcome of interest was whether parents reported consulting a physician after receiving notices that the child had a "high" value, either in the third grade, the fifth grade, or on both occasions. Chi-square analyses were used to examine the associations between the outcome and the effects of geography (site), child's actual level of cholesterol, medical insurance, ethnicity, gender, education level of parents, family history of heart disease, and reported changes in health habits.

Multiple logistic regression, with adjustment for random effects of school, was carried out using an SAS version 6.10 macro procedure to assess the strength of these associations further and to explore which combined factors best predicted the outcome (GLIMMIX, a macro for fitting generalized linear mixed models, unpublished procedure, SAS Institute, Inc, Cary, NC).[15] For the multiple logistic regression, the child's cholesterol level in two determinations (if that was the case) was averaged. Because of small sample sizes of some ethnic groups, the logistic regression was limited to children with white, African-American, and Hispanic ethnicities.

RESULTS

Figure 1 shows the distribution of children's cholesterol values at third and fifth grade for the CATCH cohort of a total of 5106 children. At baseline (third grade), the mean cholesterol was 170.3 (SD, 27.5) mg/dL.[13] The 75th percentile value was 188 mg/dL; the 95th percentile value was 216 mg/dL. Among these 5106 children, 13.5% (n = 689) were found to have cholesterol values of 200 mg/dL or greater. At follow-up (fifth grade), 3936 (77%) of the 5106 children had cholesterol values measured again; 485 (12.3%) were found to have cholesterol values of 200 mg/dL or greater. A total of 909 children were found to have values of 200 mg/dL or greater on one (n = 644) or both (n = 265) of these measurements. Parents received mailed notification of their children's cholesterol results and were subsequently contacted by the telephone survey unit. Overall, 784 (86.5%) parents (1 parent per family) responded to the survey, which included 723 mothers or female guardians and 39 fathers. Of the nonrespondents, 77.6% were either not located or not reached. Compared with the nonrespondents, the respondent's children were more likely to be white girls. The response rate was slightly higher in Louisiana (89.2%) and Minnesota (95.4%) than in California (83.7%) and Texas (76.6%).

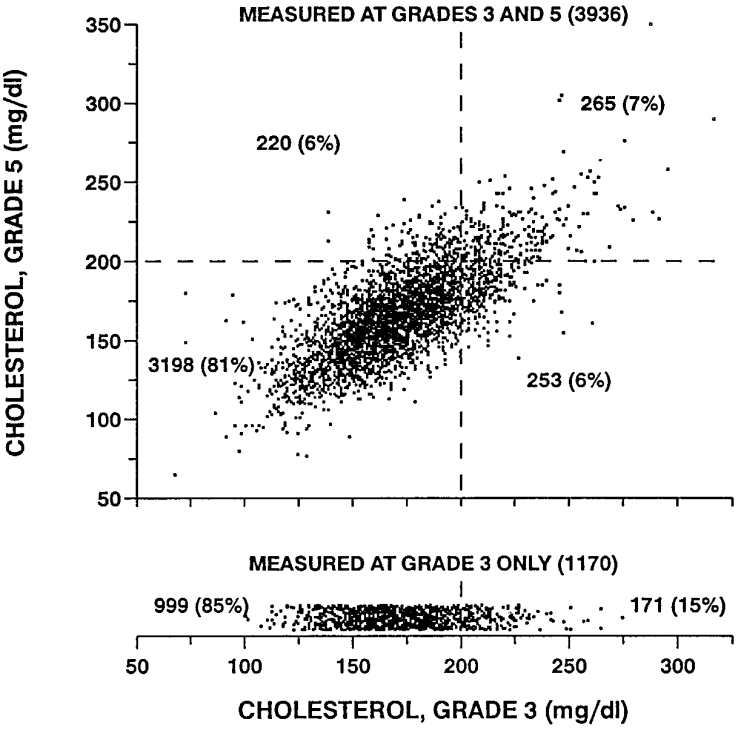

Fig 1. Distribution of total blood cholesterol, grades 3 and 5, Child and Adolescent Trial for Cardiovascular Health study. Cholesterol values for the 1170 children who had cholesterol measured only at the third grade are shown at the bottom. One hundred seventy-one (15%) were at or above the 200 mg/dL level. Distribution of cholesterol values for the 3936 children who had measurements at both the third and fifth grades are shown above, with third-grade cholesterol values plotted on the horizontal axis and fifth-grade cholesterol values plotted on the vertical axis.

TABLE 1. Child and Adolescent Trial for Cardiovascular Health (CATCH) Ancillary Study: Physician Survey Response (Sample = 179)

Ineligible	
Physician no longer at clinic where child was seen	17
Records no longer at clinic where child was seen	2
Retired/no longer seeing patients	9
Physician/clinic did not see child as patient	6
Eligible	
Completed interviews (8 of these were "second interviews" completed by physicians who saw more than one CATCH child; child data completed, personal opinions were not duplicated)	117
Physician did not see child for cholesterol	8
Not reached	6
Refused	12
Written consent required, consent form not returned by parents	2
Total eligible	145
Response rate (117 of 145)	80.7%

Parent Characteristics and Parental Knowledge and Attitudes Concerning Notification

Of the 784 parents who responded, 538 (69%) were white, 115 (15%) were African-American, 88 (11%) were Hispanic, 7 (1%) were Native American, 23 (3%) were Asian, and 13 (2%) were of other ethnicities. Of the 784 parents, slightly more were from California (27%), Louisiana (26%), and Minnesota (26%) than from Texas (20%). Approximately half (51%) had some college education, and more than three fourths (76%) had medical insurance. About half (51%) had family histories of heart disease and reported that their partners' cholesterol had been tested (51%), whereas 70% had had their own cholesterol tested. Less than one third (30%) of their own self-reported cholesterol results were considered high, whereas 41% of the partners' cholesterol results were considered high. Among the parents, 36% were smokers, and in the past 3 years, more than half (54%) of the smokers had tried to quit smoking. More than three-fourths (77%) had tried to increase their amount of exercise, 84% had attempted to cut down on fatty food, and more than half had tried to cut down on the amount of red meat or to increase the amount of carbohydrates in their diets.

Among the parent respondents, 538 (69%) were notified of their children's high cholesterol results once in either third or fifth grade, and 246 (31%) were notified twice. Among those notified once, 84% recalled receiving the notice, yet only 39% of those remembered the results as being high. Fifty-eight percent indicated that the results caused them at least some concern. In comparison, 88% of those receiving two notices recalled ever receiving any notification, and 77% of those indicated the results had caused them concern. Although more than one third (34% to 37%) of the respondents who had concerns about their children's cholesterol levels indicated they were "very or extremely concerned," less than 22% thought it caused the same level of concern in their partners or in the children themselves.

TABLE 2. Odds Ratio for Consulting a Physician After Notification of Child's High Cholesterol, From Multiple Logistic Regression

Characteristics*	Total N	Contacted Physician N (%)	Odds Ratio (95% Confidence Interval)	*P*
Notification				
Twice	236	95 (40)	2.2 (1.4–3.5)	.009
Once	505	100 (20)	1.0	
Partner cholesterol test				
Yes	372	127 (34)	1.9 (1.3–2.8)	.001
No	369	68 (18)	1.0	
Own cholesterol test				
Yes	525	162 (31)	1.9 (1.2–3.0)	.008
No	212	32 (15)	1.0	
Medical insurance				
Yes	570	171 (30)	1.9 (1.1–3.2)	.022
No	148	23 (16)	1.0	
Some college education				
Yes	371	118 (31)	1.6 (1.1–2.4)	.013
No	368	77 (21)	1.0	
Cholesterol every 10 mg/dL				
...	...	...	1.2 (1.0–1.3)	.018
Increase exercise				
Yes	573	162 (28)	1.4 (0.8–2.4)	.158
No	168	33 (20)	1.0	
Site				
CA	196	41 (21)	0.8 (0.4–1.4)	.067
LA	202	50 (25)	1.4 (0.8–2.5)	
MN	190	65 (34)	1.5 (0.8–2.6)	
TX	153	39 (25)	1.0	
CATCH group				
Intervention	440	119 (27)	1.1 (0.7–1.7)	.647
Control	301	76 (25)	1.0	
Family history				
Yes	372	106 (28)	1.0 (0.7–1.5)	.855
No	369	89 (24)	1.0	
Race				
White	538	153 (28)	0.7 (0.4–1.3)	.075
African-American	115	16 (14)	0.4 (0.2–0.9)	
Hispanic	88	26 (30)	1.0	

* Each characteristic was controlled for all the others. CATCH indicates Child and Adolescent Trial for Cardiovascular Health.

Characteristics of the Physicians' Responses

Only 179 physicians were indicated by parents to have been consulted (179 [19.7%] of 906 children). Table 1 shows the telephone survey response rate of the 179 physicians. Thirty-four of these physicians were ineligible to be interviewed for reasons listed in Table 1. Of the 145 remaining, 117 interviews (80.7%) were completed. In 8 cases, the identified physicians claimed to have not seen the children for elevated cholesterol, as claimed by the parents. Among the physicians who responded to the survey, most of them were middle-aged (mean age, 47 [SD, 10.3] years), and more than 70% were men. The majority of them were in pediatrics or family practice. More than 90% said they spent half or more of their practices in primary care activities. After the physicians saw the children, 69 (59%) evaluated the children for possible elevated cholesterol; about half of them repeated the cholesterol determinations for the children; 42% inquired about family history; 44 (38%) made suggestions for dietary management; only 12 (10%) referred the children to dietitians; and fewer recommended more exercise (9%).

Although no physicians indicated that medication had been prescribed, two parents reported that medication (type not specified) had been recommended for their children. No question was asked regarding compliance or duration of treatment. One child (in the third grade) had a cholesterol level of 210 mg/dL and a follow-up level (at fifth grade) of 169 mg/dL; the other child had a (third grade) cholesterol level of 239 mg/dL and a follow-up level (fifth grade) of 215 mg/dL.

Characteristics Associated with Consulting a Physician

Chi-squared analyses showed that several characteristics of the parents and their partners and children were associated with whether they consulted physicians. Being notified twice of the child's result ($P = .001$), having medical insurance that covered physician visits ($P = .001$), extremely high levels of concern in the respondents ($P = .001$), and having one's own ($P = .001$) or a partner's ($P = .03$) cholesterol tested were positively associated with seeking physician consultation. Although study group assignment (intervention versus control) did not influence whether a physician was consulted, families who had attempted health habit changes, such as increasing the amount of exercise ($P = .03$) and eating more carbohydrates in the past 3 years ($P = .05$), as well as indicated that the child's cholesterol level was part of the reason for these changes were also more likely to seek physician consultation. There were no gender differences related to referral, but ethnicity ($P = .004$), site ($P = .03$), and education ($P = .001$) were related. Although a number of characteristics associated with referral were candidates as independent variables in the logistic regression,

some of these were correlated with each other. For example, many respondents who had tried to cut down fatty food had also tried to increase their exercise. Similarly, parents who were notified twice expressed more concern about their children's cholesterol results.

Considering these factors, characteristics of stronger interest and more plausible correlation with the outcome were selected for inclusion in the logistic regression model (Table 2). After adjusting for race and site, parents who were notified twice were twice as likely to consult physicians ($P < .001$). Families whose adult respondents to the survey had themselves been tested for cholesterol were close to twice as likely to consult physicians for their children than those who did not ($P < .01$). In addition, the higher the child's cholesterol level, the more likely parents were to seek physician consultation ($P < .05$). Respondents who had some college education tended more to consult physicians than those who had only high school education or less ($P < .05$). Those having health insurance were twice as likely to take the opportunity to see physicians. Family history, when other factors were present, was not a significant predictor ($P = .8$). Geographic location was also not significant ($P = .07$).

DISCUSSION

The finding that 12% to 14% of healthy children were noted to have single elevated (by expert panel standards) total cholesterol values is not the most surprising finding of this study. Similar population-based studies have shown significant numbers of US children with similar results.[16–18] Given the level of debate in the medical community on the issue, what is somewhat surprising is the finding that only about one fifth of parents recalled following the recommended course of action.

The figure may be somewhat altered because of failure of recalled information. There also could be potential respondent bias to report consulting a physician. This is suggested in the finding that several physicians denied being consulted by the parents about the problem. Failure to recall information after a long period may also explain not only the substantial proportion of parents reporting not recalling the notification but also a considerable proportion not recalling the values as being high. It may be that parents had less concern because the reason for obtaining the blood test in the first place did not originate with their own physicians but, rather, originated as a side effect of participation in a research project. It also may be the case that parents do not associate blood cholesterol with increased risk of cardiovascular disease in this younger age group. They may not believe that much can be done medically at this time in response to a cholesterol value noted in children. Parents, however, may believe that lifestyle habits and behaviors such as not smoking, diet choices, and activity are more important than cholesterol levels in this age group. Luepker[19] arrives at this conclusion based on his review of attempts to improve youth health habits. Not surprisingly, the data show that higher actual values and being notified twice were significantly associated with following the NCEP guideline recommendations. Parental concern about their own or their partners' cholesterol levels was also associated, whereas the presence of a family history of cardiovascular disease, in the presence of the other predictive factors, was not a significant factor.

Analysis of physician responses to presentation of a child with an elevated value of cholesterol also shows uncertainty about complete compliance with the NCEP guidelines. After seeing the children, only 60% of physicians reported evaluating them, and only half reported repeating the test, which is the first recommendation. Not all inquired about family history, although it is possible that this had already been ascertained. Nearly 40% made dietary recommendations, but only a few made referrals to dietitians. No physician contacted admitted recommending medication, but two parents thought that medication had been recommended by physicians we were unable to contact. This finding is cause for some concern, in that NCEP guidelines generally do not recommend medication at this first stage of investigation and level of cholesterol.

CONCLUSIONS

This study suggests that the majority of parents whose children were participating in a health project for their children were not aware of or did not comply completely with suggested procedures about elevated cholesterol levels, which were drawn from expert panel recommendations. It is doubtful that serious harm was inflicted by either the parents or the investigators, because dietary modifications would be the strongest likely response to confirmation of an elevated cholesterol level. Even in recent controlled studies (Dietary Intervention Study in Children and CATCH), total cholesterol values were only modestly influenced by dietary manipulations.[12,20] Similarly, physician responsiveness to recommendations has undoubtedly been influenced by the debate surrounding the issue of adult cardiovascular disease prevention in childhood. This study reinforces the precept that if a message is not clearly and uniformly perceived, awareness and compliance in both the professional and lay communities is compromised.

We speculate that the emphasis of messages (for the lay public) related to adult cardiovascular disease prevention with youth should be on establishing healthy dietary habits and other positive health behaviors, such as not smoking and enhanced physical activity, rather than focusing on the blood cholesterol level. These population-based recommendations have been advanced by the NCEP as well. The public health effects, such as those demonstrated in the main CATCH study of influencing the school environment to promote healthful behaviors in youth, deserve more emphasis and are likely to attract more professional and lay public support.

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