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Early Childhood Chronic Illness: Comparability of Maternal Reports and Medical Records

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Objectives

The research reported here seeks to quantitatively assess the comparability of two widely used sources of information on child health: maternal reports and medical records. The analysis provides a comparison of how well maternal reports and medical provider data agree on 15 types of chronic health conditions, ranging from specific illnesses such as asthma or sickle cell anemia to broader categories such as chronic heart or orthopedic conditions, to impairments such as vision, hearing, or speech problems.

Methods

This study uses data on a nationally representative sample of 6,201 preschool aged children whose mothers participated in the 1991 Longitudinal Followup (LF) to the 1988 National Maternal and Infant Health Survey (NMIHS) and whose identified health care providers supplied medical visit data for the children. The LF and NMIHS were conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), in collaboration with a number of other agencies of the Federal Government. In the 1991 LF survey, the mothers' questionnaire included questions on chronic and acute health conditions, accidents requiring medical attention, and hospital admissions for their children that had been included in the 1988 NMIHS. The mothers were also asked to grant NCHS permission to request medical records from the children's medical providers.

Results

Kappa statistics reveal poor agreement for 12 of 15 conditions studied. Weighted prevalence estimates vary widely across sources. For some conditions, despite apparently similar prevalence estimates from the two sources, mothers' reports and medical records identified very different groups of children as "cases." Concurrence rates were lower for children from poor, less educated, and Hispanic families. Reasons for and implications of these findings are also discussed.

Early Childhood Chronic Illness: Comparability of Maternal Reports and Medical Records

by Jane E. Miller, Ph.D., Dorothy Gaboda, Ph.D., and Diane Davis, Rutgers University

Introduction

Most population-based studies of child health and health care utilization rely on parents' retrospective reports of health conditions (1–3). Because that approach to data collection depends on the ability of a parent to recall and report on a wide range of medical conditions with which they may have little familiarity, the quality of those reports is variable and uncertain. Another common source of information on child health is records of medical care providers. Medical records avoid some of the shortcomings associated with parental reports because information is filled out by trained medical providers using standard forms, and the information is typically recorded shortly after a visit. However, such information is typically available only for children who visit a particular care provider or are within one insurance plan, and cannot be used to generalize

patterns of health or health care utilization in the general population (4).

The objective of this analysis is to compare maternal reports of chronic health conditions with records from pediatric providers for a nationally representative sample of preschool-aged children. Although the reliability and validity of these sources have been evaluated for many dimensions of health and health care utilization among adults (5,6) or for pregnancy (7), there have been few evaluations of data quality for children's health conditions (8). This study uses data on approximately 6,200 children who participated in the 1991 Longitudinal Followup (LF) to the 1988 National Maternal and Infant Health Survey (NMIHS), conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC).

The core of our analysis is a comparison of how well maternal reports and medical provider data agree on 15 types of chronic health conditions, ranging from specific illnesses such as asthma or sickle cell anemia to broader categories such as chronic heart or orthopedic conditions, to impairments such as vision, hearing, or speech problems. This comparison is complex because in most instances it is not possible to say which (if either) source is correct. There is no clear "gold standard" against which to base

Keywords: *child health, evaluation, data quality, longitudinal survey*

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comparisons. For example, if mothers report a certain condition more often than doctors, that inequality alone does not demonstrate conclusively whether mothers are overreporting, doctors are underreporting, or both. By systematically evaluating the completeness and reliability of data from two of the most commonly used types of data sources on child health, these analyses provide insight into the accuracy of each source for describing levels and differentials in health conditions among young children.

Data and Methods

Data were extracted from the 1988 NMIHS and its companion 1991 LF. The live-birth component of NMIHS was based on a sample of 13,417 birth certificates for children born in 1988 and included an oversample of black infants and of low-birthweight infants. A total of 9,953 mothers, or 74 percent, responded to NMIHS. In 1988 and 1991 mothers of sampled children were sent questionnaires that requested information about demographic background, socioeconomic characteristics, and the child's health (9,10). Overall, 8,285, or 83 percent, of the mothers of live births responding to NMIHS participated in LF. The 1991 mothers' questionnaire section on child health comprised questions on chronic and acute health conditions, accidents requiring medical attention, and hospital admissions. Specific wording and methodology are described elsewhere (11). Mothers were asked whether they had *ever* been told by a doctor, nurse, or other medical provider that the sampled child had any of the health conditions shown in [table A](#).

At followup, mothers were asked to list the names and addresses of all medical care providers visited by the sampled child since birth and were asked to grant consent for NCHS to request all medical records for that child from those providers. In the 94 percent of cases for whom consent was obtained, a letter was sent to each named provider asking for information

on diagnoses and procedures that occurred at each visit (see below for details). Consent rates did not differ significantly according to sociodemographic characteristics of the mother or child. The Medical Provider Survey data file comprises 99,117 records, one for each reported visit to a medical provider. Seventy-seven percent of the nominated providers supplied medical visit data, covering a total of 6,201 children.

For each visit, medical providers were asked to fill in a checklist of possible conditions as well as an open-ended section of diagnoses for that visit. Fifty-five percent of medical providers filled out the information for each visit into the NCHS form, while the remaining 45 percent of providers attached a copy of the medical records for the sampled child. All reported conditions were categorized according to the corresponding ICD-9-CM codes (12) into categories that matched those listed on the mother's questionnaires. The visit information was then aggregated to yield measures of whether each child had ever been diagnosed with each of the specified conditions. Classification of health conditions into these categories was reviewed for accuracy and plausibility with a practicing pediatrician. The choice of which conditions to group under each of the headings is deliberately rather broad, keeping in mind that the mothers had neither special medical training nor prompts or definitions of the terms used on the questionnaire.

To analyze consistency of reporting across sources, Cohen's kappa was calculated for each of the chronic conditions. Cohen's kappa is based on the difference between the observed proportion of subjects upon whom the two informants (sources) agree, and the proportion expected by chance, given the marginal distributions (13). The kappa statistic takes into account concurrence on the noncases as well as the cases (6). Cutoffs for extent of agreement are from Landis and Koch (14).

The authors used multinomial logistic regression models of discordance in asthma reporting to assess the extent to which characteristics

of the mother or child account for the variation in concurrence rates across sources. Children for whom the mother and medical record agree are compared with those for whom the mother but not a medical provider mentioned asthma, and those for whom a medical provider but not the mother mentioned the condition. Asthma was chosen because of its importance as a child health problem (1, 15) and because it provided an adequate number of cases to support multivariate analysis ($N = 665$). The model includes only the children for whom at least one of the sources reported asthma, and is further restricted to those children for whom all nominated providers responded to the survey, to rule out incomplete response as an explanation for the discordance.

All analyses of study participation and consistency of reporting across sources are unweighted so that each sampled child represents only him and/or her. Prevalence rates in [table B](#) are weighted to the population level using the sampling weights provided by NCHS for LF, which are calibrated to be representative of children born in the United States in 1988 who were alive at the time of the followup, and incorporate adjustments for the initial sampling design as well as loss-to-followup (11).

Results

Provider Response Patterns

To provide insight into how representative the medical records data are of all children in NMIHS and LF, the authors analyzed the availability of information from medical providers and how it differs according to socioeconomic and other characteristics of the child and type of medical provider. This analysis defines the subgroup of children in the sample for whom information from medical records and parents is available. As shown in [table C](#), hospital-based providers (80 percent responding), physician's offices or HMO's (71 percent), and

Table A. Concurrence of maternal report and medical records on specified chronic health conditions, by completeness of provider response: 1991 Longitudinal Followup to 1988 National Maternal and Infant Health Survey

| Condition as worded on mother's questionnaire ¹ | Corresponding ICD-9-CM code(s) ² | Number of cases with condition ³ | | Kappa ⁴ | | Percent of cases ⁵ mentioned by: | | |
|--|---|---|--------------------------------|--------------------|---------------------|---|-----------------------|-----------------------------|
| | | Complete (N = 3910) | Partial or complete (N = 6183) | Complete | Partial or complete | Mother only | Medical provider only | Mother and medical provider |
| Deafness/other hearing problems | 388, 389, 744.0 | 273 | 435 | 0.07 | 0.09 | 32 | 61 | 7 |
| Delayed speech/other problems with speaking or understanding | 315.3, 784.5 | 208 | 377 | 0.03 | 0.02 | 97 | 2 | 1 |
| Problems with sight ⁶ | 368, 369, 743 | 114 | 195 | 0.18 | 0.19 | 64 | 25 | 11 |
| Food allergy | 693.1 | 213 | 362 | 0.11 | 0.11 | 79 | 14 | 7 |
| Other allergies/hay fever | 477, 495.9 | 544 | 895 | 0.09 | 0.08 | 77 | 16 | 7 |
| Asthma | 493 | 665 | 1,098 | 0.48 | 0.47 | 22 | 41 | 37 |
| Other chronic respiratory condition ⁶ | 491, 496, 506.4, 519.9, 770.7, V17.6 | 347 | 584 | 0.19 | 0.17 | 62 | 25 | 13 |
| Chronic heart condition | 393-459 | 136 | 217 | 0.12 | 0.16 | 40 | 51 | 9 |
| Sickle cell anemia | 282.4-282.6 | 65 | 113 | 0.19 | 0.14 | 74 | 18 | 8 |
| Spina bifida | 741 | 9 | 17 | 0.50 | 0.58 | 53 | 6 | 36 |
| Eating or swallowing problems ⁶ | 307.59, 779.3, 787.2, V41.6 | 65 | 111 | -0.01 | 0.03 | 73 | 25 | 2 |
| Developmentally delayed or mentally retarded | 317-319 | 123 | 223 | 0.19 | 0.22 | 51 | 35 | 13 |
| Epilepsy/convulsions/seizures ⁶ | 345, 779.0, 780.3 | 124 | 225 | 0.35 | 0.36 | 14 | 63 | 23 |
| Chronic orthopedic problems ⁶ | 710-739 | 259 | 398 | 0.09 | 0.15 | 27 | 63 | 10 |
| Cerebral palsy | 333.7, 343 | 42 | 81 | 0.60 | 0.56 | 40 | 21 | 40 |

NOTES: Statistics are presented aggregated to the child level (for example, across all visits to providers) Table A includes the 6,183 children for whom at least one medical provider mentioned by the mother responded to the LF. "Partial" provider response indicates that at least one of the nominated providers for the child responded; "complete" provider response indicates that all of the nominated providers for the child responded (N = 3,910).

¹Sequence and categories of conditions from the mother's questionnaire to the LF. Medical provider classifications based on ICD-9-CM codes from medical records.

²Corresponding ICD-9-CM codes used to classify information from medical records. For each child, condition could have been mentioned by an ambulatory, emergency room, or inpatient provider, or more than once by a provider.

³Number of children for whom the condition was mentioned by mother, medical provider, or both.

⁴The kappa score is a measure of the strength of agreement between the two measures. Kappa < 0.40 represents fair-to-poor agreement, 0.40-0.60 moderate agreement, and 0.60-0.80 substantial agreement. (14)

⁵Percent of cases based on sample of children for whom at least one provider responded.

⁶Wording from the mother's questionnaire: a) Problems with sight even when wearing glasses; b) Any other chronic respiratory, lung, or breathing condition; c) Eating or swallowing problems that affect his/her growth; d) Epilepsy or convulsions or seizures without fever; 4) Chronic orthopedic, bone, or joint problems.

Table B. Weighted prevalence (percent) of specified chronic health conditions from National Maternal and Infant Health Survey/Longitudinal Followup Mother's Questionnaire and Medical Provider Survey and 1988 National Health Interview Survey

| Chronic health conditions | Prevalence either ¹ report | Prevalence mother's report | Prevalence provider report | Prevalence both report | 1988 NHIS ² (less than 10 years of age) |
|--|---------------------------------------|----------------------------|----------------------------|------------------------|--|
| Deafness/other hearing problems | 7.5 | 2.5 | 5.5 | 0.5 | 1.4 |
| Delayed speech/other problems with speaking or understanding | 3.8 | 3.7 | 0.2 | 0.1 | 3.2 |
| Problems with sight ³ | 2.2 | 1.3 | 1.0 | 0.2 | 1.1 |
| Food allergy | 6.5 | 5.6 | 1.5 | 0.6 | 2.3 |
| Other allergies/hay fever | 15.5 | 12.9 | 3.7 | 1.1 | --- |
| Asthma | 13.6 | 7.7 | 10.0 | 4.1 | 3.9 |
| Other chronic respiratory condition ³ | 7.3 | 5.3 | 2.3 | 0.3 | --- |
| Chronic heart condition | 2.5 | 1.4 | 1.5 | 0.4 | 1.4 |
| Sickle cell anemia | 0.9 | 0.8 | 0.2 | 0.1 | 0.1 |
| Spina bifida | 0.2 | 0.2 | 0.1 | 0.1 | --- |
| Eating or swallowing problems ³ | 1.2 | 0.8 | 0.4 | 0.0 | --- |
| Developmentally delayed or mentally retarded | 1.9 | 0.8 | 1.3 | 0.2 | --- |
| Epilepsy/convulsions/seizures ³ | 2.9 | 1.0 | 2.5 | 0.6 | 0.2 |
| Chronic orthopedic problems ³ | 6.1 | 2.0 | 4.6 | 0.5 | --- |
| Cerebral palsy | 0.5 | 0.4 | 0.3 | 0.2 | 0.2 |

NOTES: Weighted to population levels using final sampling weight from LF. Statistics are presented aggregated to the child level (for example, across all visits to all providers). Table includes all 6,183 children for whom at least one medical provider responded to the LF.

--- Data not available.

0.0 Quantity more than zero but less than 0.05.

¹Condition mentioned by mother or medical provider.

²Based on maternal responses to a checklist of conditions for children under age 10, weighted to national levels (15).

³Wording from the mother's questionnaire: a) Problems with sight even when wearing glasses; b) Any other chronic respiratory, lung, or breathing condition; c) Eating or swallowing problems that affect his/her growth; d) Epilepsy or convulsions or seizures without fever; e) Chronic orthopedic, bone, or joint problems.

Table C. Response rates to Medical Provider Survey by characteristics of provider: 1991 Longitudinal Followup to 1988 National Maternal and Infant Health Survey

| Type of provider | Providers (N = 10,627) | | Children (N = 6,159) | |
|--|------------------------|------------------------------|----------------------------------|------------------------------|
| | Percent responding | Eligible number ¹ | Percent with provider responding | Eligible number ² |
| Ambulatory or Emergency Room | 71 | 13,099 | 82 | 7,409 |
| Physician's office or HMO ³ | 71 | 6,627 | 81 | 5,037 |
| Health center or clinic | 40 | 3,508 | 46 | 2,990 |
| Emergency department or hospital service | 79 | 3,602 | 88 | 2,906 |
| Inpatient hospital | 80 | 1,700 | 81 | 1,521 |
| Overall | 72 | 14,799 | 82 | 7,499 |

¹The eligible number of providers of each type was based on the number of providers of that type reported by mothers responding to the Longitudinal Followup. If a given child was reported to have visited more than one provider of the same type, those providers were each counted in the total. In 925 cases, a provider supplied both outpatient and inpatient hospital care to a child and is counted in both categories.

²The number of eligible children for each type of provider was based on the number of children for whom that provider type was mentioned. Each child could have visited more than one type of provider and could have visited more than one provider of the same type.

³HMO is health maintenance organization.

emergency rooms (79 percent) were nearly twice as likely as health centers or clinics (40 percent) to respond to the survey. From the perspective of the sampled children, 82 percent of children who participated in LF had information from one or more of their medical providers. For some 37 percent of children with medical provider information, at least one provider mentioned by the mother did not respond to the survey.

Factors associated with a greater chance of having no medical provider data include minority race (odds-ratios (OR) = 1.65 and 1.58 for non-Hispanic black and Hispanic children, respectively, both $p < .0001$), residence in an urban area (OR = 1.61, $p < .0001$), low maternal education attainment (OR = 1.17, $p < .05$), Medicaid insurance (OR = 1.28, $p < .0001$) or no insurance (OR = 1.17, $p < .05$), as shown in [table D](#). The same characteristics were associated with having information from some but not all providers ("partial provider response"; not shown).

Measures of Intersource Agreement

[Table A](#) presents two different measures of extent of agreement between maternal reports and medical records on each of the 15 chronic health conditions, along with the definitions of each condition according to the mother's questionnaire and the ICD-9-CM codes from the medical records. Results are shown separately for children with

complete provider response and for children with *any* provider response (for example, partial or complete provider response). Of the children with partial provider response, three-quarters were missing records from only one provider. Inclusion of all children for whom at least one provider responded increases the number of children in the analysis from 3,910 to 6,183, and increases the number of cases of each condition by 50 percent or more.

Kappa statistics for each of the conditions are quite similar for children with complete provider response as for children with any provider response, indicating little if any loss of precision from including the cases for whom some providers did not respond. The analyses described below are based on the larger, more representative sample of children for whom at least one provider responded. There is moderate agreement between sources for only three conditions—cerebral palsy (kappa = 0.56), spina bifida (kappa = .58), and asthma (kappa = 0.48)—although cerebral palsy and spina bifida approach the cutoff for "substantial agreement." To test for the possibility that terminology was not well understood, the combined category of maternal reports of "other chronic respiratory condition" or asthma was compared to a medical record indication of asthma, but the kappa statistic remained low (0.44). The remaining 12 conditions exhibit fair-to-poor agreement, many of them with kappa values at the extreme low end of its calculable range, including

values close to zero for delayed speech and eating and swallowing problems.

To show in more detail where the disagreement lies for each condition, the right-hand columns of [table A](#) list the percent of cases (that were mentioned by at least one source) that were reported only by the mother, only by a medical provider, or by both sources. For most of the conditions shown, the percent of cases reported only by the mother was slightly higher in the sample that included partial and complete provider responses, while the percent reported only by a medical provider was slightly lower (not shown). The only condition for which the pattern of discordance was notably different for the full sample than for children with complete providers was asthma.

Consistent with the kappa statistics, the level of agreement between sources is extremely low for most conditions. The percent of cases upon which the two sources agree ranges from zero concurrence for eating and swallowing problems that affect growth to 40 percent for cerebral palsy. For some conditions, including delayed speech, allergies, and sickle cell anemia, more than three-quarters of the "cases" are reported by the mother only. For other conditions, including chronic heart or orthopedic conditions and epilepsy/convulsions/seizures, and deafness or other hearing problems, at least one-half of the cases are reported only by a medical provider.

Mothers were more likely to recall and report serious cases (as measured by

Table D. Odds ratios for no provider responses to Medical Provider Survey by characteristics of the mother, family, and provider: 1991 Longitudinal Followup to 1988 National Maternal and Infant Health Survey

| Characteristic | Sample number | Odds-ratio | P-value |
|--|---------------|------------|---------|
| Age of mother | | | |
| Under 20 years | 933 | 1.02 | 0.81 |
| 20–24 years | 1,722 | 1.00 | ... |
| 25–29 years | 1,740 | 1.03 | 0.74 |
| 30–34 years | 1,163 | 1.05 | 0.57 |
| 35 years and over | 443 | @ 1.25 | 0.04 |
| Education of mother | | | |
| Less than high school | 1,282 | @ 1.16 | 0.04 |
| High school graduate | 2,528 | 1.00 | ... |
| Some college | 2,057 | 1.06 | 0.42 |
| College graduate or more | 292 | 0.81 | 0.16 |
| Family income level | | | |
| Less than 1.00 x poverty | 2,145 | 0.97 | 0.77 |
| 1.00–1.84 x poverty | 1,132 | 1.01 | 0.94 |
| 1.85–2.99 x poverty | 1,188 | 0.93 | 0.42 |
| 3.00 x poverty or more | 1,676 | 1.00 | ... |
| Race and Hispanic origin | | | |
| Non-Hispanic black | 2,769 | @ @ 1.65 | 0.0001 |
| Non-Hispanic white or other race | 2,908 | 1.00 | ... |
| Hispanic | 482 | @ @ 1.58 | 0.0001 |
| Type of insurance | | | |
| Private ¹ | 3,136 | 1.00 | ... |
| Medicaid | 2,416 | @ @ 1.28 | 0.0001 |
| Medicare | 208 | 0.94 | 0.13 |
| None | 722 | @ 1.17 | 0.04 |
| Mother's marital history | | | |
| Never married | 1,670 | 1.01 | 0.92 |
| Married by date of LF | 183 | 1.02 | 0.83 |
| Marital disruption | 338 | 0.88 | 0.34 |
| Married at NMIHS and LF dates | 3,436 | 1.00 | ... |
| Other | 532 | 1.02 | 0.93 |
| Residence | | | |
| Rural | 1,831 | 1.00 | ... |
| Urban | 6,454 | @ @ 1.61 | 0.0001 |
| Test of fit -2log likelihood = 197.6 with 19 degrees of freedom; $p < .0001$ | | | |

@Denotes $p < .05$ compared with reference category within the column.

@@Denotes $p < .01$ compared with reference category within the column.

... Category not applicable.

NOTE: "No provider response" indicates that none of the medical providers listed by the mother responded to the survey.

¹Private insurance includes group coverage, private insurance, or health maintenance organization.

instances when the child was hospitalized for the condition), however, there is surprisingly poor concurrence between maternal reports and medical records even for relatively severe cases. For example, of the 190 children with medical records indicating hospitalization for asthma, only 79 percent had their mother report that their child had ever been diagnosed with asthma. Agreement barely rises to 80 percent for the combined groups of

children hospitalized for asthma or other serious respiratory conditions ($N = 241$ children).

Weighted Prevalence Estimates

To illustrate how these levels and patterns of disagreement affect the estimated prevalence of each condition, [table B](#) presents the percent of children

with that condition according to four possible definitions of a case: 1) based on a report in either source (the most inclusive definition); 2) the maternal report, regardless of the medical record; 3) the medical record, regardless of maternal report; and 4) both sources (the most restrictive definition). Statistics in [table B](#) are weighted to the population level using the LF sampling weights.

The prevalence estimates vary widely depending on the choice of

source. Asthma rates, for example, range from 13.6 percent (either source reports the disease) to 4.1 percent (both sources report it), with rates based on medical records slightly higher than those based on maternal report (10.0 percent and 7.7 percent, respectively). The most extreme variation in rates based on the different sources is observed for conditions such as delayed speech or epilepsy for which one source reported the majority of the cases.

Characteristics Associated With Discordance Between Sources

To assess whether agreement between sources varies according to the characteristics of the mother or child, [table E](#) presents results of multinomial logistic regression models of discordance in asthma reporting. The first column contains odds-ratios for

children for whom the mother but not a medical provider mentioned asthma, while the second column contains odds-ratios for whom a medical provider but not the mother mentioned the condition, when each is compared with children for whom *both sources* reported asthma (the omitted category).

The odds that either informant reports asthma decline as mother's educational attainment increases ($p < .05$). The pattern for income is

Table E. Odds ratios from multinomial logistics model of discordance in reporting of asthma between mother and medical provider, by sociodemographic, health, and insurance characteristics for children with complete provider information: 1991 Longitudinal Followup to 1988 National Maternal and Infant Health Survey

[N = 655]

| Characteristic | I | | II | |
|---|--------------------------|---------|------------------------------------|---------|
| | Mother only ¹ | | Medical provider only ¹ | |
| | Odds-ratio | p-value | Odds-ratio | p-value |
| Age of mother | | | | |
| Under 20 years | 0.90 | 0.71 | 0.69 | 0.13 |
| 20–24 years | 1.00 | ... | 1.00 | ... |
| 25–29 years | 0.83 | 0.42 | 0.79 | 0.19 |
| 30–34 years | @ 2.32 | <0.01 | @ 1.80 | 0.01 |
| 35 years and over | 0.54 | 0.16 | 1.03 | 0.91 |
| Education of mother | | | | |
| Less than high school | 1.59 | 0.14 | 1.46 | 0.10 |
| High school graduate | 1.00 | ... | 1.00 | ... |
| Some college | 0.88 | 0.63 | 0.91 | 0.61 |
| College graduate or more | 0.35 | 0.10 | 0.85 | 0.67 |
| Family income level | | | | |
| Less than 0.50 x poverty [#] | @ 1.76 | 0.03 | @ 0.57 | 0.01 |
| 0.50–0.99 x poverty | 1.09 | 0.72 | 1.17 | 0.45 |
| 1.00–1.84 x poverty | 1.20 | 0.44 | 1.03 | 0.89 |
| 1.85–2.99 x poverty | @ 0.48 | 0.01 | 1.09 | 0.67 |
| 3.00 x poverty or more | 1.00 | ... | 1.00 | ... |
| Race and Hispanic origin | | | | |
| Non-Hispanic white | 1.00 | ... | 1.00 | ... |
| Non-Hispanic black | 0.93 | 0.81 | 0.77 | 0.20 |
| Hispanic | 1.68 | 0.22 | 1.77 | 0.09 |
| Other | 0.47 | 0.23 | 0.71 | 0.40 |
| Type of insurance ² | | | | |
| Private only | 1.00 | ... | 1.00 | ... |
| Public only | 0.79 | 0.31 | 1.26 | 0.22 |
| Private and public | 0.75 | 0.35 | 0.73 | 0.24 |
| No insurance | 1.35 | 0.29 | 1.17 | 0.55 |
| Mother's rating of child health | | | | |
| Excellent, very good, good | 1.00 | ... | 1.00 | ... |
| Fair, poor [#] | 0.76 | 0.12 | @ 0.36 | <0.001 |
| Likelihood ratio | ... | ... | 599.1 | ... |
| Degrees of freedom | ... | ... | 566 | ... |

[#]Denotes that the difference between coefficient on this variable for the mother-only versus provider-only is statistically significant at the $p < .05$ level.

@Denotes $p < .05$ compared with the reference category within the column.

@@Denotes $p < .01$ compared with the reference category within the column.

... Category not applicable.

NOTE: Analysis includes only children for whom asthma was reported by the mother or medical provider.

¹Odds-ratios and p-value are for the category shown compared with children for whom mother and medical provider reported asthma.

²Private insurance includes group coverage, private insurance, or health maintenance organization; public insurance includes Medicare, Medicaid, and military insurance.

quite different: For the poorest children there is a direct tradeoff between a greater likelihood that only the mother will report asthma ($OR = 1.76, p < .03$) and a smaller likelihood that only a medical provider will report it ($OR = 0.57, p < .01$). In other words, with increasing educational attainment, the overall level of agreement increases, with little shift between the two sources of information, whereas for poor children, the most important pattern is in the *type* of disagreement. These patterns suggest that the educational attainment pattern may relate more to understanding the symptoms and terminology of asthma, whereas the income pattern may predominantly reflect differences in access to or usage of health care.

Hispanic children are more likely than other children to have asthma reported by either of the two sources alone ($OR = 1.68$ for mother-only reports, and $OR = 1.77$ for provider-only reports, when each is compared with only non-Hispanic persons). Although they do not quite reach standard significance levels, in part because there were fewer than 50 Hispanic children in this analysis, these results are suggestive of problems with understanding and communicating the symptoms of the disease between the two types of informants. Given the small number of Hispanic children, this analysis did not differentiate between those who use English versus Spanish as their primary language. Finally, agreement levels in asthma reporting are higher among children whose mothers report that the child is in fair or poor health than for those in better health, perhaps because these children are taken to the doctor more often so that both parties are familiar with the child's health conditions. Maternal age, race, and insurance do not relate to risk of discordance in asthma reporting in the multivariate model.

Discussion and Conclusions

Analysis of a nationally representative, population-based sample survey of preschool-aged children reveals substantial inconsistency in information about children's chronic health conditions based on medical records data and maternal reports. Our findings concur with those of studies such as those from the Health Interview Evaluation Survey, which also demonstrated that "surveys and medical records often provide different pictures of the prevalence of chronic conditions in a population" (5). In our data, levels of agreement between the sources range from moderate for conditions including asthma, cerebral palsy, and spina bifida, to nearly complete discordance for eating or swallowing problems and delayed speech. In a comparison of maternal reports and physical examination results using data from the National Health and Nutrition Examination Survey, Jessop and Stein (8) also found little overlap in the identification of children's chronic health conditions in the two sources, and hence wide variation in prevalence estimates depending upon which source or sources were used. Consistent with our results, they also found that parents often did not report chronic heart, neuromuscular or joint conditions that were diagnosed in the medical examination, and that maternally-reported asthma was often not mentioned in the clinical findings; similar patterns across conditions have also been observed for adult health (6).

The importance of a comparison of parental reports and medical records for a *uniform* nationally representative sample is driven home in our findings about chronic heart conditions. Although at first glance the two sources appear to yield quite similar estimates of the prevalence of this condition in the NMIHS/LF sample (1.4 percent and 1.5 percent for maternal reports and medical records, respectively), closer examination reveals that the two sources are reporting almost completely nonoverlapping groups. Fewer than

16 percent of the cases reported by either source are reported by both sources. This type of information cannot be obtained from a comparison of estimates drawn from different studies or samples as in a review of published literature (8). For example, prevalence estimates from a study of maternal reports might or might not be close to prevalence estimates from a study of medical records, but it is not possible to determine whether the different sources are capturing similar groups of children, and hence, to assess the reliability of either source.

Our finding that there is substantial disagreement between maternal reports and medical records of children's chronic illness has important repercussions for the practice of medicine. First, there is evidence of considerable misunderstanding among parents about their children's health conditions, with some cases of serious health conditions overlooked while others appear to be overstated. For example, nearly two-thirds of mothers whose children had been diagnosed with epilepsy, convulsions, or seizures by a medical provider did *not* report that health condition even when specifically asked about it on a questionnaire. The lack of awareness or poor understanding of these conditions among these children's primary care givers is likely to pose a significant hindrance to appropriate preventive care and treatment for these conditions. On the other hand, parents were much more likely than physicians to report problems with eating or speech that may have had little clinical significance and could lead to inappropriate focus of resources on those perceived problems.

Also disconcerting is the relatively high proportion of cases of some conditions that were not reported by a medical provider. Although this could be the result of overreporting on the part of the mother, there is evidence that even fairly serious conditions may not be diagnosed in some children. For example, one study showed that a substantial share of school-aged children had clinical evidence of asthma despite a lack of a physician's diagnosis of the condition (16). This problem is likely to occur disproportionately among poor

children and others who lack health insurance. Particularly for chronic conditions that require regular management and monitoring of symptoms, the absence of a medical diagnosis raises the risk that the severity of these conditions will escalate, increasing the financial, health, and developmental costs of the illness.

In addition to the clinical consequences, there are several implications of these findings for the interpretation and collection of data on children's health conditions. First, any estimates based on information from the medical records in NMIHS/LF must be corrected for selective nonresponse. In our data, for example, because medical provider's response rates are lower for children served by clinics, who are typically from lower socioeconomic groups, differentials across income groups may be understated by medical records data. These differentials will be further exaggerated by the fact that children from low income or minority families are medically underserved—an issue that will affect many other medical records databases (5).

Another important consideration for interpretation of data from NMIHS/LF is that estimates of prevalence rates from one or the other source may be either high or low, depending on the condition and the source. Previous studies of other data sets, age groups, and health conditions have also concluded that agreement between medical records and self-reports varies across conditions or for different levels of severity and should not be generalized (6). Hence, it is important to assess which source is likely to provide more valid data for a given condition, and to understand the types of biases that affect reporting of that condition by each source before analyzing information from any of these types of sources.

Our analyses suggest that access to care, communication issues, understanding about children's health conditions, and recall problems all contribute to the observed discrepancies between maternal reports and medical records of those conditions. The evidence regarding access to care comes from results of our models of asthma

reporting, which showed that among poor children, there was a much higher likelihood of parent-only reports and a much lower likelihood of medical records-only reports than among higher income children. Data from the 1987 National Medical Expenditures Survey showed that children who lack health insurance are 80 percent to 100 percent more likely than children with medical insurance to go without a visit to a physician for asthma and other health problems even when medical care is indicated (17). Children who do not receive adequate "well-baby" care or visit a doctor only when ill are especially unlikely to be screened for normal development because "sick visits" tend to focus on a specific complaint rather than the child's overall health and development. Furthermore, it is more difficult to assess other conditions when a child is not feeling well.

Because low-income children had fewer health care visits, particularly well-child visits, they are less likely to have existing conditions diagnosed. In their assessment of questionnaire and medical records data for adults, Harlow and Linet (6) concluded that use of medical records for assessing accuracy of adults' self-reports of medical conditions is not appropriate for conditions that depend on self-identification of health problems and care-seeking behavior on the part of the patient, and these concerns should be applicable to children's health conditions as well.

Results of other studies suggest that differences in usage of care for different conditions may affect reporting patterns (5). Statistics from the 1988 National Health Interview Survey show that physician contacts and hospitalization rates were quite low for impairments such as hearing, vision, and speech problems, but were more common and more variable for diseases and other health conditions (15). Statistics from the survey showed that 5 out of 6 asthmatic or epileptic children, but only one out of six children with heart disease, were reported as using medication, while hospitalization was relatively frequent for diabetes and epilepsy. These statistics are consistent

with reporting patterns observed in the NMIHS data, such as the fact that mothers were far more likely than medical providers to report perceptual impairments, but that medical providers were more likely to report epilepsy.

Poor communication or a lack of understanding of medical terminology also appears to affect concurrence between sources (8, 18). If a medical provider uses technical jargon to describe a child's health condition, that wording may match the questionnaire used in a survey like NMIHS/LF but may not be understood or remembered by the mother. Conversely, if a medical provider uses lay terms to describe a condition, the mother might understand and recall those terms, but they will not match the wording on the questionnaire. Whether the average parent of a 3-year-old is familiar with the clinical meaning of words such as "chronic," "orthopedic," or "developmental delay" is unclear. If they use some other definition, the likelihood of discordance increases. Further, physicians may be more likely to name specific conditions than to describe the broad category to which a condition belongs, so that a parent may not know that arthritis is an orthopedic condition, for example. The lack of clear, unambiguous diagnostic criteria and wording on questionnaires increases the chance of inconsistent and incorrect reporting on health conditions (6) because the definitions are likely to have differed across mothers, although the extent of this problem cannot be assessed by the data at hand.

A related concern is that the terms used to name or describe a given health condition vary across providers or among people of different language, cultural, or educational backgrounds (7,19). For example, asthma is called "wheezy bronchitis" by some doctors and is referred to as "fatiga" among Latinos (20). In our study, Hispanic children and those with low maternal educational attainment were more likely to have asthma and other health conditions reported by their mother but not a medical provider, even for children with complete medical records.

Issues of parental vigilance and the absence of specified criteria by which the mother could evaluate clinical

significance may also help to explain the apparent overreporting of some conditions by mothers. Two conditions for which there were much higher rates of reporting by mothers are eating and/or swallowing problems that interfere with growth, and delayed speech and/or problems speaking or understanding, both of which are prominent issues in the daily lives of parents of preschool-aged children such as those in the NMIHS/LF sample. Many 3-year-old children have not yet achieved clear speech, and there is considerable variation in how well children in this age group can speak and understand speech. Although physicians are trained to distinguish normal speech and language development from that which is truly delayed, most parents are not. It may be that some of the mothers who are reporting delayed speech are being hypervigilant in evaluating their child's speech and are overreporting problems, whereas medical providers may be reporting only clinically meaningful speech problems. The mothers' questionnaire does not offer any definition of these terms or basis upon which to assess the child's performance. The fact that there may not have been formal, systematic screening of all children for some conditions (such as speech delay) by age 3 years, may also explain some discrepancies in mother's and doctor's diagnoses. For example, if formal screening for language problems does not occur until a child is 4 years old, mothers may be correct in their assessment, but there may be no basis for verification in the child's medical records.

Other studies provide indirect evidence about the possible importance of parental assessment of the salience of other types of health conditions. In an analysis of data from NHIS, Newacheck and Taylor (15) showed that only 10 percent of mothers reported that their asthmatic children were never bothered by their condition, compared with 75 percent of those with heart disease. Given these differences in the frequency and severity of current consequences of these two conditions, it makes sense that mothers would be more likely to recall asthma than a chronic, but minor, heart

condition. Conditions that have only occasional, mild symptoms may not be reported in the survey (21). Illnesses that have current consequences are also more likely to be recalled (18), hence a health condition that has been corrected may not be reported. Other studies have also shown that people are more reluctant to report conditions that are stigmatizing (6,21), such as mental retardation.

Recall issues may also be responsible for poor concurrence between sources. Because patient or proxy (such as parent) reports in many health surveys are collected retrospectively for health histories that span several years, they may suffer from various types of recall bias. Mothers may be more likely to omit less serious health conditions (18), to misplace dates of occurrence (22), or to incorrectly remember the names of health conditions that were diagnosed several months or years in the past (23,24). In contrast, information is typically recorded in the medical record shortly after the time of a visit. However, if records for one or more visits are omitted or miscoded, it is possible that a particular diagnosis may be overlooked. As a consequence of these issues, we expect that estimates based on maternal reports will be lower than those based on medical records because of the longer recall period pertaining to maternal reports.

A final note of caution is that some of our findings may not be generalizable to data from other studies because of differences in target populations and other design factors. NMIHS/LF included only preschool aged children, which means that some conditions may not have onset or have yet been diagnosed. An older expected onset will also affect whether children have been screened for some conditions by age 3. For example, older children may be more likely to have been screened for conditions such as vision or speech, so that maternal reports on those conditions might be more accurate for older children. On the other hand, other age groups may lead to different types of data collection problems such as a longer recall period for older children.

Another design factor is that the NMIHS/LF data were collected with self-administered, written questionnaires that did not contain prompts or definitions of terms, so our findings may not be generalizable to other data collection methods, such as those that are symptom- or consequences-based (5). However, surveys such as the National Health Interview Survey or the medical history portion of the National Health and Nutrition Examination Survey that use a checklist to collect information on chronic conditions often do not include definitions of the terms or lists of related symptoms to provide a consistent definition across subjects, hence maternal report information from those studies may well be subject to similar types of biases.

Finally, the reliability and validity of information from other studies of medical provider data may also differ from that collected in NMIHS/LF because of methodological differences. For example, data collected by physical examination at some specified point in the child's lifetime (for example, the NHES or examination data from the NHANES) will differ from that abstracted directly from a child's medical records (for example, NMIHS/LF) because the latter yields estimates of lifetime prevalence, while the former yields estimates of current prevalence. The conclusions drawn in this paper should be generalizable to other studies of children's chronic illness based on a series of medical records, but may not apply to health examination surveys.

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