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Validation study

Low-income minority mothers’ reports of infant health care utilisation compared with medical records

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Summary


This study aimed to investigate mothers’ reporting of the nature, location, frequency and content of health care visits for their infants, as compared with data abstracted from the infants’ medical records. It was part of a community-based parenting intervention designed to improve preventive health care utilisation among minority mothers in Washington, DC. Mothers ≥18 years old with newborn infants and with poor or no prenatal care were enrolled in the study. A total of 160 mother–infant dyads completed the 12-month study. Mothers were interviewed when the infants were 4, 8 and 12 months old, and were asked to recall infant visits to all health care providers. Medical records from identified providers were used for verification. The number and type of immunisations given, types of providers visited, and reason for the visits were compared.

Only about a quarter of mothers agreed with their infants’ medical records on the number of specific immunisations received. The mothers reported fewer polio (1.8 vs. 2.1, \( P = 0.006 \)), diphtheria and tetanus toxoids and pertussis (DTP) (1.8 vs. 2.2, \( P = 0.002 \)), and Haemophilus influenzae type b (HiB) (1.3 vs. 2.1, \( P < 0.0001 \)) immunisations than were recorded. Similarly, about a quarter of the mothers were unaware of any polio, DTP or hepatitis B immunisations given, as documented in the medical records, and 38% did not know that their infant was immunised for HiB. Nearly half of the mothers recalled more infant doctors’ visits than were recorded in the medical records (4.1 vs. 3.6 visits, \( P = 0.017 \)). The mothers generally disagreed with the providers about the reason for a particular visit and reported fewer sick-baby visits (1.5 vs. 3.3, \( P < 0.0001 \)) than the providers recorded. Mothers’ reports and medical records matched in only 19% of the cases. In 47%, mothers under-reported and in 34% over-reported the total number of visits. The strongest agreement between mothers’ reports and medical records was in the case of emergency room visits (63%). In conclusion, in this population, mothers’ reporting did not match that of providers with respect to specific immunisations: the number of immunisations, the location where services were provided, and the classification of sick- vs. well-baby visits. Future studies that evaluate health care utilisation data should take these discrepancies into consideration in their selection of information source, and in their interpretation of the data.

Keywords: immunisation, health care, maternal recall, medical records, recall bias.
Introduction

Infant and childhood morbidity and mortality are directly related to access to and use of perinatal and paediatric preventive health care services.\textsuperscript{1–3} Research suggests that efforts to increase infant health care utilisation may be important in reducing infant morbidity and mortality, particularly among low-income minority populations.\textsuperscript{4,6} Data from parents, providers, medical records and administrative databases have previously been used in epidemiological studies documenting infant health care utilisation, but accuracy of parental report is rarely addressed. One approach is to compare the documented medical records and parents’ reports of the frequency and content of health care visits.

Studies comparing medical records and patient recall in adults have found under-reporting and over-reporting in both the number and types of provider visits.\textsuperscript{7–14} Several studies have addressed parental recall of infant and childhood immunisations with varying results. While all show that parents’ reports and medical records do not agree, some have found that parents tend to under-report specific immunisations, including diphtheria and tetanus toxoids and pertussis (DTP), oral polio vaccine (OPV), and/or measles, mumps and rubella (MMR).\textsuperscript{15,16} Still others found that parents over-report immunisation status, particularly for MMR.\textsuperscript{17,18} Very little is reported on the comparability of the parents’ reporting of a sick vs. well visit and the infant’s medical record. It is important to obtain accurate infant health care utilisation data to evaluate the impact of preventive health maintenance on both infant mortality and infant well-being.

This paper investigates mothers’ reporting of the frequency of health care visits for their infants, compared with data abstracted from the infants’ medical records. It addresses the agreement between mothers’ and providers’ records in the volume of services provided. In addition, it examines the agreement between mothers’ and medical records on whether the visit was a well or sick visit, and whether an immunisation was given and specifically the type of immunisation. The study population was a group of low-income African-American mothers who had themselves used prenatal care (PNC) minimally during pregnancy, a strong predictor of poor health care utilisation for their infants. The goal of this analysis is to evaluate mothers’ reports of health care utilisation for their infants during the first year of life.

Methods

Study design

This analysis was conducted using data from the Pride in Parenting (PIP) study, part of the National Institutes of Health – District of Columbia Initiative to Reduce Infant Mortality in Minority Populations. The PIP study was a randomised, controlled trial designed to test the efficacy of a community-based intervention to improve preventive health care usage among low-income minority mothers receiving no or inadequate PNC in Washington, DC. The goals of PIP were to improve health care utilisation and infant growth and development in this at-risk population. It was hypothesised that an intervention focusing on parenting skills as part of a ‘self-efficacy’ curriculum could improve maternal use of preventive infant health care and consequently infants’ survival. The PIP study’s design and main findings have previously been published.\textsuperscript{19}

Participants

Mothers and their newborn infants were enrolled in PIP at four hospitals in Washington, DC, during the immediate postpartum period. The study was conducted between April 1995 and April 1997. To be eligible for the study, mothers were required to be at least 18 years of age, residents of the District of Columbia, non-institutionalised, and having no history of psychiatric illness. All mothers received either inadequate or no PNC during their pregnancies, defined as fewer than five PNC visits or care initiated during the third trimester. Mother–infant dyads were excluded from participation if their infants were born <34 weeks of gestation, weighed <1500 g at birth, or had congenital abnormalities, as any of these factors could directly influence patterns of health care utilisation. The institutional review boards of all participating institutions approved the protocol, and all participants were provided with written informed consent to participate in the intervention programme.

Eligible mothers who agreed to participate were randomised into either the intervention or the control group. Those in the intervention group received a multi-component intervention that included social services support as well as home visiting and group intervention. Mothers in the control group received standard social services support. Details of the intervention programme are presented elsewhere.\textsuperscript{20,21}
A total of 286 mother–infant dyads were enrolled in PIP. Due to the high mobility of this high-risk population, attrition was high. By 4 months there were 210 mothers retained in the study, 188 by 8 months, and 168 at 12 months. Data from eight women were dropped from the analyses because no chart abstractions were available. A comparison of the women who dropped out with those who were retained in the study has been previously published, although it is worthwhile to note that no differences were found on the baseline questionnaire measures of attitudes about health care, child rearing or perceived social support. Mothers retained in the study had fewer living children, more PNC visits, and a lower percentage of them had received no PNC. This analysis includes the 160 infants whose mothers completed a 12-month interview and for whom medical records were abstracted.

Data collection

A baseline interview designed to gather sociodemographic information was administered to each mother at the time of recruitment and prior to her discharge from the hospital. To reduce the chances of memory lapse and recall bias, mothers were interviewed at 4, 8 and 12 months following delivery to obtain information regarding the health care utilisation of their infants. At each time period, they were asked to recall visits made for their infants to all types of health care providers (HCPs) since the previous interview, including doctors, clinics, emergency rooms and hospitals. For each visit, the mother was asked to report the following information: (1) the visit date; (2) the name and type of the provider [public clinic, private clinic, health maintenance organisation (HMO) plan, private doctor, hospital in-patient, hospital outpatient, emergency room or other]; (3) the reason for the visit, including: well-baby check-up; immunisations; injury; illness; or other; (4) if immunisations were received, the type of immunisation specified by the mother, including OPV or inactivated polio, DTP, Haemophilus influenzae type b (HiB), hepatitis B and MMR; and (5) any tests that were conducted, including for anaemia, lead and tuberculosis (TB).

In addition to providing information about these health care visits, the mother was also asked to provide written consent to release medical record information from each provider she named at each interview. These medical records were abstracted from the identified providers and used to verify the mother’s reporting of the health care utilisation for her infant. Each visit was abstracted separately for each infant and independently from the mothers’ reports. During the review of the medical records, if additional visits were documented in the record but not reported by the mother, such visits were also abstracted. The same type of information that the mother provided was obtained from the infants’ medical records, including the type of provider, reason for the visit, immunisations given, and tests conducted. Attempts were made to verify all infant visits made to providers by 12 months of age.

Medical records abstractors were trained during a centralised, 2-day training session conducted by the data coordinating centre. To ensure consistency in data collection among abstractors, they were initially sent to the abstraction sites in pairs. Each conducted an independent abstraction, and the pairs were reviewed by a trained medical advisor and discrepancies were identified and resolved.

Statistical methods

Health care services were broken down into several separate categories, corresponding to the type of information obtained from the mother and medical record. These categories included polio, DTP, HiB and hepatitis B immunisations; anaemia and TB tests; visits to doctors’ offices and emergency rooms; and well- and sick-baby visits. Within each category, the total number of visits to all providers that the mothers reported, as well as the services provided, was counted. Similarly, for each infant, the total number of services recorded by the various providers in each category was summed.

The mothers’ reporting of each service category was dichotomised to reflect whether or not the service was provided at least once during the infant’s first year of life. The medical records obtained from all providers for an infant were combined to create similar outcome variables. Two-way cross-tabulations were used to compare the mothers’ reports and providers’ records of these services. Kappa statistics were calculated to examine the proportion of agreement between mothers’ and medical records beyond that which would be expected by chance. Landis and Koch have provided interpretation of the kappa statistic: 0.00–0.20, poor agreement; 0.21–0.40, fair agreement; 0.41–0.60, moderate agreement; 0.61–0.80, substantial agreement; and 0.81–1.00, almost perfect agreement. However, the kappa statistic is sensitive to the
prevalence and number of values or ‘categories’ within a variable.\textsuperscript{24,25}

Two types of analyses were conducted in order to examine the extent of agreement between mothers and their infants’ medical records in the number of services provided for each category. Descriptive statistics were first used to characterise the level of agreement between mothers and providers’ records. For each service category, the infants were placed into one of three groups: (1) infants for whom a greater number of services were recorded in the medical record; (2) infants for whom a greater number of services were reported by the mother; and (3) infants for whom the mother and medical records agreed on the number of services provided. The percentage of infants in each group was calculated. Next, the Wilcoxon Signed Rank Test was used to determine whether there were systematic differences in the number of services reported by mothers and providers. This test was selected for use, as opposed to a paired \( t \)-test, because the range in the number of services provided was often small and not normally distributed.

\textbf{Results}

\textit{Characteristics of the participants and providers}

Table 1 presents characteristics of the mothers who were included in this analysis. Participants identified 60 infant HCPs, which included 18 hospitals, 24 public and private community-based clinics, and 18 individuals in private practice. These HCPs were located almost entirely in Washington, DC and surrounding suburbs. Medical records could not be obtained from six HCPs (mainly in other states); this affected 26 visits (2\%) reported by the mothers, which were therefore excluded from all analyses. The mothers reported a total of 1159 visits to an HCP, and 1141 visits were abstracted from the medical records. On average, the infants received care from 1.5 providers before their first birthday, and had made approximately six medical visits during this time.

\textbf{Agreement in services provided at all visits}

Table 2 presents the analysis of mother–HCP agreement according to the various service types: immunisations, laboratory tests, visit locations and visit classification. For polio, DTP and hepatitis B vaccinations, the majority of mothers agreed with the records on whether the immunisations had been given. However, when there was disagreement, 20–25\% of the mothers did not report that documented immunisations had been given. A higher percentage of mothers (38\%) did not report that their infants received the HiB titre, although it was documented. The kappa statistics for each individual immunisation indicate poor agreement between mother and provider.

The results of analysis for anaemia and TB tests follow a different pattern. Mothers and the HCP agreed that the majority of infants did not receive either of these tests by 1 year of age. Among mothers who disagreed with the records for anaemia testing, 60\% did not report a documented test. For TB testing, the disagreement was split fairly evenly between mothers reporting that the tests had and had not been done. The kappa statistic for anaemia tests indicates poor agreement (\( \kappa = 0.19 \)), while for TB tests there is moderate agreement (\( \kappa = 0.45 \)).

There was fair agreement in reporting whether or not doctors’ office/clinic visits had taken place (\( \kappa = 0.27 \)), and substantial agreement for emergency room visits (\( \kappa = 0.62 \)). There was also fair agreement on whether or not the visits were for well-baby visits (\( \kappa = 0.24 \)) or for illness (\( \kappa = 0.33 \)). However, nearly 25\% of the mothers reported at least one visit when no visits were recorded. Furthermore, 93\% of disagreements for sick-baby visits occurred when the HCP indicated that

\begin{table}[h]
\centering
\caption{Maternal demographic characteristics}
\begin{tabular}{ll}
\hline
Characteristic & \( n \) (\%) or mean \pm SD \\
\hline
Maternal age & 24.9 ± 6.1 \\
Black/African-American & 158 (98.8\%) \\
Education & \\
Less than high school & 68 (42.5\%) \\
High school degree & 75 (46.9\%) \\
Beyond high school & 17 (10.6\%) \\
Never married & 144 (94.7\%) \\
Working before birth & 67 (50.4\%) \\
Currently working & 47 (29.6\%) \\
Insurance & \\
Medicaid & 65 (41.9\%) \\
Medicaid managed care & 42 (27.1\%) \\
Managed care/private & 27 (17.4\%) \\
Self/none & 21 (13.5\%) \\
Number of pregnancies & 3.6 ± 2.1 \\
Number of living children & 2.88 ± 1.5 \\
Week of PNC initiation & 26.7 ± 6.1 \\
Number of prenatal visits & 4.1 ± 2.9 \\
\hline
\end{tabular}
\end{table}

PNC, prenatal care.

\textit{Comparison of mothers’ reports with medical records}\textsuperscript{277}
the reason for visit was illness, but the mother did not. Conversely, 74% of the disagreement for well-baby visits occurred when the mother indicated that the reason for the visit was a routine check-up but the HCP did not.

Table 2. Agreement that services were provided

<table>
<thead>
<tr>
<th>Service</th>
<th>Both Yes n (%)</th>
<th>Both No n (%)</th>
<th>Total agreement n (%)</th>
<th>Mother yes/provider no n (%)</th>
<th>Mother no/provider yes n (%)</th>
<th>Total disagreement n (%)</th>
<th>Kappa coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immunisations⁴</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polio</td>
<td>107 (66.9)</td>
<td>7 (4.4)</td>
<td>114 (71.3)</td>
<td>10 (6.3)</td>
<td>36 (22.5)</td>
<td>46 (28.8)</td>
<td>0.10</td>
</tr>
<tr>
<td>DTP</td>
<td>103 (64.4)</td>
<td>7 (4.4)</td>
<td>110 (68.8)</td>
<td>11 (6.9)</td>
<td>39 (24.4)</td>
<td>50 (31.3)</td>
<td>0.07</td>
</tr>
<tr>
<td>HiB</td>
<td>79 (49.4)</td>
<td>12 (7.5)</td>
<td>91 (56.9)</td>
<td>8 (5.0)</td>
<td>61 (38.1)</td>
<td>69 (43.1)</td>
<td>0.08</td>
</tr>
<tr>
<td>Hepatitis B</td>
<td>97 (60.6)</td>
<td>12 (7.5)</td>
<td>109 (68.1)</td>
<td>9 (5.6)</td>
<td>42 (26.3)</td>
<td>51 (31.9)</td>
<td>0.16</td>
</tr>
<tr>
<td>Any immunisation</td>
<td>113 (70.6)</td>
<td>7 (4.4)</td>
<td>120 (75.0)</td>
<td>7 (4.4)</td>
<td>33 (20.6)</td>
<td>40 (25.0)</td>
<td>0.15</td>
</tr>
<tr>
<td>Laboratory tests</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anaemia</td>
<td>15 (9.4)</td>
<td>97 (60.6)</td>
<td>112 (70.0)</td>
<td>19 (11.9)</td>
<td>29 (18.1)</td>
<td>48 (30.0)</td>
<td>0.19</td>
</tr>
<tr>
<td>Tuberculin</td>
<td>10 (6.3)</td>
<td>131 (81.9)</td>
<td>141 (88.1)</td>
<td>11 (6.9)</td>
<td>8 (5.0)</td>
<td>19 (11.9)</td>
<td>0.45</td>
</tr>
<tr>
<td>Visit locations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor’s office/clinic</td>
<td>105 (65.6)</td>
<td>13 (8.1)</td>
<td>118 (73.8)</td>
<td>38 (23.8)</td>
<td>4 (2.5)</td>
<td>42 (26.3)</td>
<td>0.27</td>
</tr>
<tr>
<td>Emergency room</td>
<td>53 (33.1)</td>
<td>77 (48.1)</td>
<td>130 (81.3)</td>
<td>12 (7.5)</td>
<td>18 (11.3)</td>
<td>30 (18.8)</td>
<td>0.62</td>
</tr>
<tr>
<td>Visit classification</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well baby</td>
<td>137 (85.6)</td>
<td>4 (2.5)</td>
<td>141 (88.1)</td>
<td>14 (8.8)</td>
<td>5 (3.1)</td>
<td>19 (11.9)</td>
<td>0.24</td>
</tr>
<tr>
<td>Sick baby</td>
<td>102 (63.8)</td>
<td>17 (10.6)</td>
<td>119 (74.4)</td>
<td>3 (1.9)</td>
<td>38 (23.8)</td>
<td>41 (25.6)</td>
<td>0.33</td>
</tr>
</tbody>
</table>
| aPolio indicates OPV (oral polio vaccine) and/or IPV (inactivated polio vaccine); DTP indicates diphtheria–tetanus–pertussis; HiB indicates Haemophilus influenzae type b.

Table 3. Agreement in number of services provided

<table>
<thead>
<tr>
<th>Service</th>
<th>Provider reporting &gt; mother reporting n (%)</th>
<th>Provider reporting = mother reporting n (%)</th>
<th>Provider reporting &lt; mother reporting n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immunisations⁴</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polio</td>
<td>66 (41.3)</td>
<td>48 (30.0)</td>
<td>46 (28.8)</td>
</tr>
<tr>
<td>DTP</td>
<td>66 (41.3)</td>
<td>47 (29.4)</td>
<td>47 (29.4)</td>
</tr>
<tr>
<td>HiB</td>
<td>83 (51.9)</td>
<td>43 (26.9)</td>
<td>34 (21.3)</td>
</tr>
<tr>
<td>Hepatitis B</td>
<td>61 (38.1)</td>
<td>46 (28.8)</td>
<td>53 (33.1)</td>
</tr>
<tr>
<td>All immunisations</td>
<td>81 (50.6)</td>
<td>17 (10.6)</td>
<td>62 (38.8)</td>
</tr>
<tr>
<td>Laboratory tests</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anaemia</td>
<td>35 (21.9)</td>
<td>104 (65.0)</td>
<td>21 (13.1)</td>
</tr>
<tr>
<td>Tuberculin</td>
<td>8 (5.0)</td>
<td>140 (87.5)</td>
<td>12 (7.5)</td>
</tr>
<tr>
<td>Visit locations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor’s office/clinic</td>
<td>52 (32.5)</td>
<td>30 (18.8)</td>
<td>78 (48.8)</td>
</tr>
<tr>
<td>Emergency room</td>
<td>43 (26.9)</td>
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<td>16 (10.0)</td>
</tr>
<tr>
<td>Visit classification</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well baby</td>
<td>53 (33.1)</td>
<td>37 (23.1)</td>
<td>70 (43.8)</td>
</tr>
<tr>
<td>Sick baby</td>
<td>110 (68.8)</td>
<td>33 (20.6)</td>
<td>17 (10.6)</td>
</tr>
<tr>
<td>Total visits to providers</td>
<td>75 (46.9)</td>
<td>31 (19.4)</td>
<td>54 (33.8)</td>
</tr>
</tbody>
</table>

³Polio indicates OPV (oral polio vaccine) and/or IPV (inactivated polio vaccine); DTP indicates diphtheria–tetanus–pertussis; HiB indicates Haemophilus influenzae type b.

Agreement on frequency of services provided

Table 3 provides the level of agreement between mothers and HCPs on the number of services provided during the infants’ first year of life. Table 4 compares
the mean number of times each service was provided as reported by the mother and documented in the medical record.

For each of the four immunisations examined, only about 30% of mothers reported the same number of immunisations given to their child as was recorded. Table 4 reveals that mothers reported significantly fewer polio, DTP and HiB vaccinations than documented in the medical record. Although agreement was not better for hepatitis B, the difference in reporting was not significant. This is because, among mothers who did not report the same number as documented by the HCP, approximately half reported more than the HCP, and half reported fewer. Thus, there was no systematic difference between the two sources.

Tables 3 and 4 reveal that the mothers’ reporting of laboratory tests was more comparable with the records. The differences between the mothers’ reports and HCP records were not significant for either type of test. This agreement could be a reflection of the specificity of TB testing including the observation of the injection site over a period of days which may have increased the likelihood of recall. In the case of anaemia, mothers may have been more likely to remember testing since the providers could have discussed the results of the test with the mother and occasionally may have prescribed medication.

In terms of the location of the visits, the kappa coefficient was strongest for emergency room visits, where there was 81% agreement on whether at least one such visit had been made. In the case of a doctor’s office/clinic visit, 74% of mothers agreed with the medical records on whether at least one visit occurred, while 24% of mothers reported office/clinic visits that were not corroborated by medical records review. Overall, mothers reported more visits than physicians recorded. Nearly half (49%) of the mothers recalled taking their infant to a doctor’s office/clinic more times than was recorded in the medical record. A higher percentage of mothers (63%) agreed with providers on the number of emergency room visits, yet the average number of visits reported by mothers was significantly lower than recorded by providers (0.6 vs. 0.9, \( P < 0.001 \)).

Tables 3 and 4 also reveal that mothers’ reports do not generally agree with their infants’ medical records about the reason for a particular infant visit. Mothers were more likely to report a higher number of well-baby visits and fewer sick-baby visits than was documented. Overall, only 19% of mothers matched HCP reports of the number of times that they took their baby to see any HCP for any reason. The mothers were more likely to either under-report (47%) or over-report (34%) the number of visits as compared with medical

<table>
<thead>
<tr>
<th>Service</th>
<th>Mothers’ reporting Mean (range)</th>
<th>Providers’ reporting Mean (range)</th>
<th>Mean difference (mother–provider) ± SD</th>
<th>( P )-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immunisations (no. of doses given)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polio</td>
<td>1.8 (0–5)</td>
<td>2.1 (0–6)</td>
<td>-0.3 ± 1.5</td>
<td>0.006</td>
</tr>
<tr>
<td>DTP</td>
<td>1.8 (0–5)</td>
<td>2.2 (0–6)</td>
<td>-0.4 ± 1.6</td>
<td>0.002</td>
</tr>
<tr>
<td>HiB</td>
<td>1.3 (0–5)</td>
<td>2.1 (0–5)</td>
<td>-0.8 ± 1.7</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Hepatitis B</td>
<td>1.4 (0–5)</td>
<td>1.5 (0–4)</td>
<td>-0.1 ± 1.4</td>
<td>0.426</td>
</tr>
<tr>
<td>All immunisations</td>
<td>6.4 (0–19)</td>
<td>7.9 (0–20)</td>
<td>-1.5 ± 1.4</td>
<td>0.002</td>
</tr>
<tr>
<td>Laboratory tests (no. of tests)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anaemia</td>
<td>0.3 (0–3)</td>
<td>0.4 (0–6)</td>
<td>-0.1 ± 0.8</td>
<td>0.072</td>
</tr>
<tr>
<td>Tuberculin</td>
<td>0.1 (0–2)</td>
<td>0.1 (0–1)</td>
<td>0.0 ± 0.4</td>
<td>0.503</td>
</tr>
<tr>
<td>Visit locations (no. of visits)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor’s office/clinic</td>
<td>4.1 (0–15)</td>
<td>3.6 (0–19)</td>
<td>0.6 ± 3.6</td>
<td>0.017</td>
</tr>
<tr>
<td>Emergency room</td>
<td>0.6 (0–3)</td>
<td>0.9 (0–9)</td>
<td>-0.3 ± 1.0</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Visit classification (no. of visits)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well baby</td>
<td>3.5 (0–9)</td>
<td>3.3 (0–10)</td>
<td>0.3 ± 2.4</td>
<td>0.165</td>
</tr>
<tr>
<td>Sick baby</td>
<td>1.5 (0–10)</td>
<td>3.3 (0–19)</td>
<td>-1.8 ± 2.7</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Total visits to providers</td>
<td>5.8 (0–18)</td>
<td>6.4 (1–27)</td>
<td>-0.6 ± 3.5</td>
<td>0.123</td>
</tr>
</tbody>
</table>

*aThe Wilcoxon Signed Rank Test was used to determine whether there were systematic differences in the number of services reported by mothers and providers.

*bPolio indicates OPV (oral polio vaccine) and/or IPV (inactivated polio vaccine); DTP indicates diphtheria–tetanus–pertussis; HiB indicates Haemophilus influenzae type b.
records. The under- and over-reporting mathematically balanced out so that the mean difference in the total number of visits was not significant.

Discussion

The current literature emphasises the lack of agreement between medical records and reports of health care utilisation from patients or parents of infants and children receiving care. The extent of agreement or disagreement varies with the service provided. The greatest agreement between these sources is found in emergency medical services and acute health events, and the least is found in preventive health care services and chronic illnesses. These differences can be explained partially by recall bias, when parents’ reporting is affected by the acuity of the event and the length of the recall period. Some studies have additionally suggested that accuracy of parents’ reporting may be influenced by socio-economic status, although other studies have shown no effect of maternal occupation or education.

Parental recall of immunisation status for their infant appears to be particularly problematic due to the multiple immunisations and complicated dosing schedule. Although parents may be able to report their child’s general immunisation status (i.e. whether their child is ‘up-to-date’), they are less likely to accurately provide the specific immunisation regimen, as compared with their child’s medical records.

In this study, the reporting of the average number of visits by the mother did not differ significantly from the number indicated by the medical record review. Over-reporting by some mothers cancels the under-reporting by others, resulting in an artificial agreement between mothers’ and providers’ reporting of average number of visits. There were more systematic differences between the mothers’ report and the medical records with regard to the nature, content and location of the visit(s).

In terms of the nature of the visit, a significantly higher percentage was documented in the medical record as sick-baby visits. Although preventive or well-baby services could have been provided during the visit, any concurrent illnesses may have influenced the classification by the provider, especially as sick visits are reimbursed at a higher rate than well-baby visits. Previous studies have shown that mothers, regardless of education, are able to report accurately on their children’s acute medical conditions. The level of agreement between the mothers’ reports and medical record review varies by the severity of the illness, being greater for bronchial asthma, bronchitis and accidents than for other illnesses such as otitis media. Thus, it is possible that recorded sick visits by providers in our study were attributable to less severe concurrent illnesses.

With respect to content of the visit, we have focused on two areas, immunisations and laboratory testing. Various studies in the literature indicated that parental reporting of immunisation status for their infants and children may over- or underestimate the number actually received. The degree of agreement between parents’ and physicians’ reports is inversely related to the length of the recall period and the number of doses required for a particular immunisation. Agreement also varies with the type of immunisation, and ranges from 8% for the complete and specific immunisation regimen to 34% for DTP and OPV. The agreement for individual doses of an immunisation is higher, ranging from 71% to 83% for individual doses of DTP and polio. Unfortunately, only one study has included the HiB titre in its analysis of parent–provider agreement and specific results are not reported for it. No studies have examined the accuracy of reporting of hepatitis B immunisations during infancy.

Despite the low educational level of mothers participating in this study, they agreed in 57–71% of cases with the provider’s report on whether the infant had received a particular immunisation. This dropped to 27–30% when the number of doses was being recalled. These rates are consistent with previous reports. There were varying levels of disagreement between the documented immunisations in the medical record and those reported by mothers. This was significant for polio as well as DTP, but was most significant in the case of the HiB titre, where the mothers may not have been familiar with it, or may have confused it with other immunisations such as hepatitis B. The providers reported more immunisations than the mothers on average except in the case of hepatitis B, where the medical records were almost equally as likely to have documented more or fewer immunisations as the mothers’ reports. There are clinical implications associated with the parents’ assumption that their infants are protected against a particular infection if the infants had not received the appropriate immunisation. Inaccurate reporting to other HCP’s by the mothers regarding their infants’ immunisation status and potentially a false sense of security during an exposure event may have

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significant health consequences. This emphasises the importance of further educating parents on HiB titre and hepatitis B vaccines because parents were less able to correctly identify receipt of these immunisations.

There did not seem to be a significant difference between the mothers’ reporting and infants’ medical records on anaemia testing and TB testing. Perhaps this is because the majority of infants had not received either test by the end of the first 12 months of life.

In terms of location, two important factors seem to play a role. The severity of an illness may influence the ability of the mother to remember an emergency room visit. The relative rarity of an emergency room visit may also influence the likelihood of a mother’s recollection. A source of confusion in misclassifying a visit as a regular visit by the mother instead of an emergency visit is because frequently urgent care is provided in the same clinic space after usual hours. Because it is the same location, mothers may misclassify it as a clinic visit.

This study emphasises the limitations of health care utilisation data collected through patient/parent interview and medical record abstraction. Both methods inherently may be biased: the former by recall and by the level of understanding of the patient/parent of services that have been provided, and the latter by billing preferences and limitations. These biases should be considered when interpreting the literature for purposes of public health evaluation and policies. An underestimate of immunisations received (parent reporting) and of preventive health care services provided (medical record abstractions) are both misleading. Electronic medical records may resolve the issue of inaccuracies of reporting by the patient/parent, but may not adequately correct the bias of classification of visit by the provider. Prospective research following services as they are provided may be considered a gold standard but may be impractical and very resource intensive.

Conclusion

The strengths of this study include its prospective design with data collection at short intervals. In addition, it is among the first to describe maternal reporting on HiB and hepatitis B immunisations. One of the limitations includes a high attrition rate among participants, which is not unusual in such a high-risk minority population. Also, we were unable to collect data on study participants who had obtained care outside the Washington DC area, although this was a very small number.

In this high-risk, low-income minority population, mothers’ reporting did not match that of providers with respect to specific information: the number of immunisations, the location where services were provided, and the classification of sick- vs. well-baby visits. Compared with medical records, mothers under-reported the number of immunisations given to their infants and either under- or over-reported the number of visits made to an HCP. These findings support the idea of creating electronic immunisation registries, whether local or national, in order to ascertain accuracy, standardisation and completeness of reporting.

Furthermore, mothers and providers did not agree on the classification of visits. Providers were more likely to record illness visits, while mothers reported well-baby check-ups. Similar results were given by Ronsaville and Hakim. Designation of the purpose of the medical visit in the physician’s record may be skewed by billing preferences and therefore may not be considered a gold standard. This study is an unbiased evaluation of reporting by mothers and physicians and confirms that neither can be considered a gold standard. Future studies that evaluate health care utilisation data should take these discrepancies into consideration in their selection of information source, and in their interpretation of the data. The African-American mothers included in this study, despite relatively low educational and socio-economic status, did not seem to differ from what has been reported in the literature on the general population. This could be attributed to the relatively short time period between the provision of the service and the maternal interview in our study.

Acknowledgements

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References


Did you spot? Continued

**Childhood accidents**

Korea: deaths under 5 years of age. Children had lower risk in families with mothers who were highly educated, whose fathers were in non-manual occupations; those in rural or highly deprived neighbourhoods had high rates.

**Stress and infection**

USA: 897 pregnant women. Unadjusted associations were high for bacterial vaginosis and measures of stress, but the effect size diminished substantially once confounders such as age, race and income were taken into account.

**Diarrhoea in childhood**

Pakistan: Mothers assessed at 3 months post delivery – 130 clinically depressed and 135 non-depressed followed up for 1 year. Ascertainment of diarrhoea in the infants was carried out every 2 weeks; children of women who had been depressed had significantly more episodes of diarrhoea.

**Statistical methods**

This useful paper is part of the celebrations for the 25 years in which the journal Statistics in Medicine has been in existence. It summarises very usefully the development of this topic. Issues of study design and analysis are covered comprehensively.