Whether and Why Pediatric Researchers Report Race and Ethnicity

Catherine Walsh; Lainie F. Ross, MD, PhD

Background: Recently, specific policy statements have been published in pediatric journals that question the use of race and ethnicity (R/E) in health care research.

Objectives: To determine why researchers may or may not collect R/E data and to find out their opinion on the importance of R/E and SMs to their research.

Methods: All full-length articles published in the print edition of 3 general pediatric journals published between July 1, 1999, through June 30, 2000, were collected and reviewed. Articles were excluded if they did not include at least 1 US researcher, all subjects at US institutions, some prospective data collection, or enrolled less than 8 or more than 10,000 subjects. We recorded whether the articles documented R/E, socioeconomic markers (SMs), or both in the “Results” section and whether they discussed their significance. Corresponding authors (or researchers) were surveyed to clarify the R/E data, to determine why they had or had not collected R/E data, and to elicit their opinion on the importance of R/E and SMs to their research.

Results: One hundred ninety-two studies qualified for further review. One hundred fourteen (59%) reported R/E but only 44 (23%) discussed it. Even fewer 74 (39%) reported both R/E and SMs, and only 33 (17%) discussed both. Researchers collected R/E data because they thought it was relevant and because it described the subject population. Seventy-five percent of the researchers who responded to the survey thought R/E and 63% thought SMs were relevant to their research, and this influenced whether they reported and discussed R/E ($P < .001$, $\chi^2$ test) and whether they discussed SMs ($P < .001$, $\chi^2$ test).

Conclusions: Pediatric statements will require that researchers not mention R/E or explore the extent to which R/E disparities are confounded by other SMs. This will require a cultural shift because many researchers believe that R/E is relevant to their research, and yet, they infrequently report SMs.


In June 2000, the American Academy of Pediatrics Committee on Pediatric Research published a subject review on the effects of sex, race and ethnicity (R/E), and socioeconomic status (SES) on child health. The American Academy of Pediatrics noted that these factors influence child health, but argued that it is no longer sufficient to use these categories as an explanation.1 Rather, the American Academy of Pediatrics recommended the collection and analysis of data relevant to the underlying social mechanisms.1

Likewise in February 2001, the editors of the Archives expressed concern regarding the imprecision of the terms “race” and “ethnicity.”2 They stated that many studies in which race or ethnicity is mentioned as an explanatory variable are attempting to measure other SES characteristics instead. The editors requested that authors not use R/E as explanatory variables when the underlying constructs are variables that can and should be measured directly, although they acknowledged the importance of using these terms to target attention and resources to overcome current health disparities.2

In this article, we examine the extent to which pediatric researchers were reporting R/E data prior to these statements and whether the researchers were reporting other demographic data that might help explain R/E differences. In addition, we examine whether the pediatric researchers believe that R/E was relevant to their research and whether they believe that socioeconomic markers (SMs) might be more useful than R/E.

METHODS

**RESULTS**

Overall, 526 studies were examined and 192 studies qualified for further study. Table 1 summarizes whether the articles reported and/or discussed R/E or any other SMs in the article. One hundred fourteen (59%) reported R/E and 44 (23%) discussed R/E. More articles reported and/or discussed R/E than reported and/or discussed SMs. The reporting of SMs varied tremendously with some articles stating that all subjects had a public aid medical card and other articles reporting detailed educational, job, and income data. All articles that discussed R/E or SMs reported such data except 1 article in which SMs were discussed but not reported. Only 74 (39%) reported both R/E and SMs and only 33 (17%) discussed both.

We considered whether the reporting or discussing of R/E was related to the type of research (eg, therapeutic vs nontherapeutic) or the invasiveness of the research. The reporting and discussing patterns did not vary between the types of research.

One hundred ninety-two corresponding authors were sent 1 of 2 surveys, depending on whether R/E data were (n=114) or were not (n=78) reported in their articles. Authors of 14 articles (7.3%) could not be located, and 32 authors (16.6%) did not respond to the survey. Of the 146 responses, 19 refused to participate. Response rates were similar between those who reported and those who did not report R/E data.

Authors of articles that did not report R/E were asked whether they collected such data. Twenty-six (57%) of 46 respondents answered that they had collected R/E data. They were also asked why they had collected it, as were authors of articles that reported R/E. Table 2 lists the reasons why researchers collected (or did not collect) and reported (or did not report) R/E data. The most common reason for collecting and reporting these data was that the researchers thought the information had possible relevance to their research (58/77 or 75%).

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### Table 1. Reporting or Discussing Race/Ethnicity (R/E) and Social Markers (SMs) in Pediatric Research in 192 Published Articles*

<table>
<thead>
<tr>
<th>Variable Reported</th>
<th>Discussed</th>
</tr>
</thead>
<tbody>
<tr>
<td>R/E</td>
<td>114 (59)</td>
</tr>
<tr>
<td>SMs</td>
<td>92 (48)</td>
</tr>
<tr>
<td>R/E or SMs</td>
<td>132 (69)</td>
</tr>
<tr>
<td>R/E and SMs</td>
<td>74 (39)</td>
</tr>
</tbody>
</table>

*Data are given as the number (percentage) of articles.

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### Table 2. Why Collect or Not Collect Race/Ethnicity Data

<table>
<thead>
<tr>
<th>Reason</th>
<th>Why Collect</th>
<th>Why Not Collect</th>
</tr>
</thead>
<tbody>
<tr>
<td>And Report (n = 77)</td>
<td>And Not Report (n = 26)</td>
<td>Why Collected Total (N = 103)</td>
</tr>
<tr>
<td>IRB required</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>NIH required</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Peer-review journal required</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Describe population</td>
<td>26</td>
<td>8</td>
</tr>
<tr>
<td>Relevant or irrelevant</td>
<td>58</td>
<td>10</td>
</tr>
<tr>
<td>Tradition to do so</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Previously reported</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Abbreviations: IRB, institutional review board; NIH, National Institutes of Health.

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*Pediatrics and Adolescent Medicine*—from July 1, 1999, through June 30, 2000, were collected and reviewed. The 1999-2000 academic year was chosen because the authors of these articles would not have been influenced by the recent recommendation of the American Academy of Pediatrics Committee on Pediatric Research or the editorial in the *Archives*. Articles were excluded if they did not include the following: (1) at least 1 US researcher, (2) all subjects at US institutions, and (3) some prospective data collection. Articles were also excluded if they were case studies with fewer than 8 subjects or studies that involved more than 10,000 subjects, studied a population other than children and/or their parents (eg, health care providers), reviewed data from medical records or databases, used banked tissue samples, or used national survey data.

We recorded whether the articles documented R/E in the “Methods” or “Results” section of the studies (hereafter referred to as “Results”); whether they discussed R/E in the discussion, limitations, or conclusions of the article (hereafter referred to as “Discussion”); and whether they reported on any other SM (eg, specific SES measurements, public or private insurance, parental marital status, single-parent home, parental or household income, parental educational level, parental employment, welfare recipient [Aid to Family With Dependent Children], community location as inner city or suburban, father involvement, child’s school status, child’s out-of-home placement, or neighborhood income) in the “Results” section, and whether they discussed R/E or other SMs in the “Discussion” section. We did not examine whether other demographic factors like age, sex, or pubertal status were recorded, discussed, or mentioned in the article.

Corresponding authors (or researchers) were invited to participate in a voluntary survey that sought to clarify R/E data reported in the articles and to elicit the corresponding author’s opinions on the importance of R/E and SMs to their topic of study. If researchers reported the R/E of their subjects, they were asked why they did so. If they did not report the R/E, they were asked if they had collected the data, whether they could provide it to us, and why they chose not to report it. If they did not report R/E data because they did not collect it, they were asked why they chose not to collect it. In addition to asking all corresponding authors if they believed that R/E was relevant to their area of study, they were asked to select any SM from a provided list which corresponded to data collected from articles, that they believed, could be more explanatory. Corresponding authors’ answers to open-ended questions were coded for analysis on receipt of the surveys or completion of the structured telephone interviews. Corresponding authors were sent 2 e-mails and received a follow-up telephone call. If the corresponding author’s contact information could not be obtained, the first author or last author of the study was contacted.

Both approval from the University of Chicago institutional review board for the project and waived written consent were obtained prior to contacting any of the corresponding authors of the articles. Data were analyzed using a commercially available computer program SPSS for Windows Version 11.0.1 (SPSS Inc, Chicago, Ill). Statistical significance was set at P<.05.
four researchers collected R/E data because they wanted to describe their study population, but only 26 (76%) chose to report it. Half of those who answered that they collected R/E data because the National Institutes of Health required them to do so, chose not to report these data.

Twenty researchers did not collect R/E data. The main reason was that they did not think it was relevant to their research. In addition to the reasons listed in Table 2, the following additional reasons were given: oversight or homogeneous group (n = 3), concern regarding the accuracy of the data (n = 2), concern that it could lead to discrimination (n = 2), and either too cumbersome or unnecessary (n = 2).

One hundred twenty respondents answered whether they thought R/E was relevant. Ninety-one (75.8%) thought it was relevant. Table 3 examines whether their belief that R/E was relevant affected their decision to report or discuss R/E. Clearly, more respondents who thought that R/E was relevant reported and/or discussed R/E. About one fourth of those who did not think R/E was relevant reported it, but none discussed it. Whether they believed race was relevant was only statistically significant in the reporting of race (P < .001, χ² test).

Table 4 summarizes whether respondents thought SMs were as or more useful than R/E in their research. One hundred fifteen answered this question; 72 (62.6%) thought SMs were more relevant. Again, more respondents who thought SMs were useful reported and/or discussed them. Still, 30% of those who did not believe they were relevant reported SMs and 7.0% discussed them. Whether they believed SMs were as or more relevant was statistically significant in determining whether they reported and discussed SMs (P < .001, χ² test).

**COMMENT**

Concerns regarding the utility and validity of R/E categories in medical research began almost 2 decades ago. Despite this, the use of racial and ethnic variables has been increasing over this period. More recently, in 1997, the International Committee of Medical Journal Editors revised their statement on uniform requirements for manuscripts submitted to biomedical journals. The revised statement declares: “Identify the age, sex, and other important characteristics of the subjects. The definition and relevance of race and ethnicity are ambiguous. Authors should be particularly careful about using these categories.” All 3 pediatric journals are signatories to this document, and thus one can expect that even data collected before the 2 pediatric statements were published would conform to this requirement. Nevertheless, we have shown elsewhere that there is wide variability of reporting of R/E data and there is no consistency regarding classifications and measurements. Similar inconsistencies have been found in health psychology research, as well as in data collected by the Centers for Disease Control and Prevention.

In 1998, Bennett and Bhopal examined US health journal editors’ opinions and policies on research in R/E and health. They found that many editors did not perceive that R/E issues were germane to the research published in their journals. The editors also responded that problems related to R/E such as imprecise measurements, inappropriate aggregations, or an unclear purpose for its inclusion were not commonly encountered in research manuscripts. Bennett and Bhopal, however, argued that most of the sampled journals do publish studies in which R/E problems exist and that R/E data are frequently analyzed as explanatory variables.

Our data support the concerns of Bennett and Bhopal. In 59% of the articles, R/E was reported. However, while most researchers do report R/E, in only one third of the articles in which R/E is reported do the authors discuss the relevance of R/E to their findings (44/115). In addition, one third of the articles that reported R/E data did not report any SMs (40/115), and one fourth that discussed R/E did not discuss SMs (11/45), suggesting that the researchers are using R/E as an explanatory variable rather than looking for the underlying mechanisms.

Some researchers have found that many (but not all) of the health disparities found in minority communities can be accounted for by correcting for other SMs. Others argue that the failure of SES to completely account for racial variations in health status emphasizes the need for health researchers to give more systematic attention to the unique factors linked to race that affect health including racism, migration, acculturation, and a comprehensive assessment of SES. We found, however, that both R/E and SMs were only mentioned in 39% of the studies and discussed in less than 20% of the studies. Clearly, this is inadequate if one believes that R/E are risk markers and not risk factors.

Why then do researchers collect and report R/E data? Clearly, many researchers (76%) believe that this infor-
This study begins to examine the role of R/E in pediatric research published in pediatric journals. It shows that researchers believe that R/E is relevant to their research and that they have traditionally not examined the potential underlying SMs that may explain some, if not most, of the racial and ethnic differences.

Second, our decision to review data from the 1999-2000 academic year was to avoid any manuscript revisions that might be recommended after the publication of the American Academy of Pediatrics statement in June 2000, and the editorial in the ARCHIVES published in February 2001. Nevertheless, in answering our survey, it was interesting to see if there is a change in reporting and statements in response to our survey. Clearly, it would be interesting to see if there is a change in researchers’ attitudes now that these policies are in place.

Third, we documented an article as reporting SMs if it made any mention of an SM. In actuality, the relationship between health and SES is complex and different measurements (eg, income and educational level) have a different effect on different communities. Thus, the number of articles that actually provide enough data on SMs to examine the underlying social mechanisms behind R/E differences is smaller than we suggested in Table 1. Because of the variability and incompleteness of data on SMs, we were unable to make any inferences about whether SMs changed the effect of R/E. Clearly, if the editors of pediatric journals were to insist that researchers who believe it is necessary to report R/E variables discuss their meaning, it will be necessary for those researchers to collect and report significant amounts of cultural, behavioral, and socioeconomic markers. This will require the research community to devise standardized categories and to develop consensus guidelines on what and how many of these SMs need to be collected.

Our data found that R/E are frequently reported but less commonly discussed suggesting that they may have less relevance than the researchers believe. Given that R/E data are markers for significant health disparities, one would want to know the extent to which these disparities are confounded by other SMs. Our data found that this is done in less than 20% of all research. The practice of researchers who seek to publish in pediatric research journals will need to change if they plan to conform to the American Academy of Pediatrics statement and the editorial in the ARCHIVES. Given the high percentage of researchers who thought that R/E was relevant to their research, editors may find researchers resistant to these changes.

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REFERENCES