Whether and Why Pediatric Researchers Report Race and Ethnicity

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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. 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.

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

All full-length articles published in the print edition of 3 general pediatric journals—Pediatrics, Journal of Pediatrics, and Archives of...
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</th>
<th>Reported</th>
<th>Discussed</th>
</tr>
</thead>
<tbody>
<tr>
<td>R/E</td>
<td>114 (59)</td>
<td>44 (23)</td>
</tr>
<tr>
<td>SMs</td>
<td>92 (48)</td>
<td>60 (31)</td>
</tr>
<tr>
<td>R/E or SMs</td>
<td>132 (69)</td>
<td>71 (37)</td>
</tr>
<tr>
<td>R/E and SMs</td>
<td>74 (39)</td>
<td>33 (17)</td>
</tr>
</tbody>
</table>

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

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>IRB required</td>
<td>26 (8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>NIH required</td>
<td>5 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Peer-review journal</td>
<td>1 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Describe population</td>
<td>34 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Relevant or irrelevant</td>
<td>58 (12)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Tradition to do so</td>
<td>13 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Previously reported</td>
<td>3 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

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

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 2 surveys, depending on whether R/E data were reported (n = 114) or not (n = 78) 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%).
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 by the Centers for Disease Control and Prevention 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. 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.

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.

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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.

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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