A National Mental Health Profile of Parents of Children With Medical Complexity

Nathaniel D. Bayer, MD,a Hongyue Wang, PhD,a Justin A. Yu, MD, MSb, Dennis Z. Kuo, MD, MHS,c Jill S. Halterman, MD, MPH,a Yue Li, PhDd

abstract

OBJECTIVES: The mental health of parents of children with medical complexity (CMC) is poorly understood, yet it drives child and family health outcomes. For parents of CMC, compared with parents of noncomplex children with special health care needs (CSHCN) and children without special health care needs (non-CSHCN), we examined self-reported mental health, knowledge of community sources for help, and emotional support.

METHODS: Using parent-reported data from the combined 2016–2017 National Survey of Children’s Health, we divided the population into 3 groups: households with CMC, noncomplex CSHCN, and non-CSHCN. We compared these groups regarding the following: (1) parents’ risks for poor or fair mental health and knowledge of where to go for community help and (2) parent-reported sources of emotional support.

RESULTS: Of 63,955,588 parent-child dyads (weighted from a sample of 65,204), parents of CMC had greater adjusted odds of reporting poor or fair mental health compared with parents of noncomplex CSHCN (adjusted odds ratio [aOR] 2.0; 95% confidence interval [CI] 1.1–3.8) and non-CSHCN (aOR 4.6; 95% CI 2.5–8.6). Parents of CMC had greater odds of not knowing where to find community help compared with parents of noncomplex CSHCN (aOR 2.1; 95% CI 1.4–3.1) and non-CSHCN (aOR 2.9; 95% CI 2.0–4.3). However, parents of CMC were most likely to report receiving emotional support from health care providers and advocacy groups (P < .001).

CONCLUSIONS: Among all parents, those with CMC were at the highest risk to report suboptimal mental health. They more often reported that they do not know where to find community help, but they did say that they receive emotional support from health care providers and advocacy groups. Future researchers should identify ways to directly support the emotional wellness of parents of CMC.

WHAT’S KNOWN ON THIS SUBJECT: Parents of children with medical complexity and children with special health care needs are stressed and psychosocially challenged by their care responsibilities. Their emotional wellness and their sources of support from health care providers and the community are poorly understood.

WHAT THIS STUDY ADDS: Parents of children with medical complexity, compared with parents of noncomplex children, were more likely to report poor or fair mental health and insufficient knowledge of community help. However, they were also more likely to report receiving support from providers and advocacy groups.

Children with medical complexity (CMC) are an important group in the health care system. Although they represent 0.4% to 1.9% of the pediatric population,1-3 these children account for 30% of the total health care spending in pediatrics.2 Because the majority of CMC live at home, the responsibilities of direct care and care coordination rest mainly with parental caregivers, whose efforts profoundly influence their well-being and family life.4

For children with chronic conditions, higher levels of family functioning are associated with improved quality of life (QoL), treatment adherence, and physical health.5 Parents’ emotional well-being and community and emotional support are key drivers of family functioning.6 Therefore, national organizations, CMC clinician experts, and family stakeholders have identified family health, well-being, and community support as high-priority targets for the national research agenda.7-9 Parents’ mental health and wellness are linked to family well-being, but the association of child medical complexity with parent mental health and community support has not been well described.10

To address this gap, we aimed to test the hypothesis that parents of CMC in a large national data set would have the highest odds of poor or fair mental health compared with parents of other noncomplex children with special health care needs (CSHCN) and children without special health care needs (non-CSHCN). In addition, because community support is key to the functioning of parents and the family unit, we sought to compare knowledge of community help and sources of emotional support among these 3 groups of parents.

METHODS

Data Source
Our study was a secondary data analysis of the combined 2016-2017 National Survey of Children’s Health (NSCH) data set. The NSCH characterizes the biopsychosocial health of noninstitutionalized children in the United States aged 0 to 17 years. The US Census Bureau administers the survey.11 Caregivers of systematically selected households were invited to complete the questionnaire online or through the mail, answering questions with reference to one randomly selected child from each household. During the 2016 and 2017 administrations of the NSCH, data were collected on 71,811 children. The overall weighted response rate was 40.7% for 2016 and 37.4% for 2017.12 Our university’s institutional review board deemed this study exempt.

Study Sample
Using recently published methods developed by Yu et al,13 we categorized children in the sample into 3 mutually exclusive categories based on their level of medical complexity status: CMC, noncomplex CSHCN, and non-CSHCN. This method first classifies children as CSHCN and non-CSHCN using the well-established CSHCN Screener contained in the survey: children experiencing ≥1 health consequence because of a condition lasting ≥12 months.14 Second, a subset of CSHCN are classified as CMC if their survey item responses affirmed diagnoses and health consequences corresponding to all 4 domains of the medical complexity framework developed by Cohen et al,15 namely functional limitations, chronic conditions, high health care use, and family service needs.

We restricted the sample to biological or adoptive parents, who represented >90% of all responses.

We excluded responses of nonparents, including grandparents, aunts and uncles, other relatives and nonrelatives, and foster and stepparents, who constituted such a small part of the sample that analysis of their responses would have been underpowered to examine the studied constructs.

Outcome Measures
Main outcomes were the self-reported mental health of the parent and knowledge of where to find community help. The item to measure mental health was the following question: “In general, how is your mental or emotional health?” Responses were dichotomized for analysis as follows: poor or fair versus good, very good, or excellent. This approach for self-rated health is statistically appropriate and consistently employed for analysis of NSCH data.16-19 Knowledge of community sources for help was assessed with the question “To what extent do you agree with these statements about your neighborhood or community?” with the following statement: “When we encounter difficulties, we know where to go for help in our community.” Responses were dichotomized as follows: definitely disagree or somewhat disagree versus definitely agree or somewhat agree.

Secondary outcomes included parent-reported sources of emotional support with parenting or raising children, which included health care provider, advocacy group related to child’s health condition, parent’s counselor or mental health professional, spouse, family member, place of worship or religious leader, and peer support group. Additional outcomes were parent’s self-reported level of physical health (“In general, how is your physical health?” with responses...
dichotomized as follows: poor or fair versus good, very good, or excellent), feelings toward their child (“During the past month, how often have you felt that your child is much harder to care for than most children his or her age?” with responses dichotomized as follows: never or rarely versus sometimes, usually, or always), and ability to handle the demands of raising children (“In general, how well do you feel you are handling the day-to-day demands of raising children?” with responses dichotomized as follows: not at all or not very well versus somewhat well or very well).

**Independent Variables and Household and Child Covariates**

The independent variables in the models were the levels of child medical complexity. Reference groups for the multivariate analysis included noncomplex CSHCN and non-CSHCN. Covariates were sociodemographic characteristics of children and households, including child sex, child age, child race, child ethnicity, parent sex, parent age, parent’s highest level of education, household language, family structure (2 parents, married; 2 parents, not married; single parent; or other), household income relative to poverty level, health insurance, and US region of residence.

**Analyses**

We used $\chi^2$ tests to compare across the 3 levels of child medical complexity the following variables: sociodemographic characteristics, parent mental health, knowledge of community sources of help, sources of emotional support, feelings toward their child, and ability to handle the demands of raising children. All data were analyzed by using SAS version 9.4 (SAS Institute, Inc, Cary, NC). To generate national estimates, in all analyses, we used person-level weights adjusted for the combined two-year data and combined survey strata according to guidance provided by the NSCH in their methodology report.12

We used multivariable logistic regression models to estimate the adjusted odds ratios (aORs) of parents reporting (1) poor or fair mental health, (2) not knowing where to find help in the community, and (3) secondary outcomes, including parent’s feelings toward their child and ability to handle the demands of raising children. For each model, responses from parents of CMC were compared with those from parents of noncomplex CSHCN and parents of non-CSHCN. Models controlled for the child and family demographics described above. Because the household income data had missing values for 18.6% of the sample, data with multiple imputation were entered for analyses that included income in accordance with published guidance.12 As a sensitivity analysis, we investigated the relationship between not knowing community sources for help and poor mental health by including the variable not knowing where to find help in the community as an independent variable in the logistic regression predicting poor or fair mental health. All hypothesis tests were two-sided, and $P \leq .05$ was considered significant.

**RESULTS**

**Demographics**

We included 63 955 588 parent-child dyads (unweighted 65 204), excluding ~9% of the NSCH sample who were nonparents. Among the children included, 1.5% ($n = 959 626$) were CMC, 16.5% were noncomplex CSHCN, and 82.0% were non-CSHCN (Table 1). Most parent respondents were women. The average parent age was 39.9 years (SE 0.1 year). A higher proportion of parents of CMC were women compared with parents of noncomplex CSHCN and parents of non-CSHCN ($P < .001$). Households of CMC were more likely than those of the other two groups to have parents with lower education levels and lower incomes ($P < .001$).

**Outcomes**

A higher proportion of parents of CMC (18.6%) self-reported poor or fair mental health than parents of non–medically complex children (8.7% of parents of noncomplex CSHCN and 3.5% of parents of non-CSHCN; $P < .001$) (Table 2). Nearly 25% of parents of CMC reported poor or fair physical health, compared with 10% of parents of noncomplex CSHCN and 5% of parents of non-CSHCN ($P < .001$).

Among all parents, >75% reported having someone they could turn to for day-to-day emotional support with parenting over the past 12 months. Parents of CMC were more likely than parents of noncomplex CSHCN or non-CSHCN to report that they received emotional support from health care providers, their own counselor or mental health professional, and advocacy groups related to their child’s health condition ($P < .001$). Among the subgroup of parents who reported poor or fair mental health and reported a source of emotional support, more parents of CMC (79.2%) reported receiving emotional support from mental health professionals than parents of noncomplex CSHCN (48.1%) and parents of non-CSHCN (21.6%) ($P < .001$).

In adjusted analyses, we found that parents of CMC had significantly greater odds of reporting poor or fair mental health compared with parents of noncomplex CSHCN (aOR 2.0; 95% confidence interval [CI] 1.1–3.8) and parents of non-CSHCN (aOR 4.6; 95% CI 2.5–8.6) (Table 3).
In addition, parents at increased odds of reporting poor or fair mental health were female, younger, unmarried, and not college educated and had a lower household income.

Overall, 77.2% of parents of CMC reported they felt that their child was sometimes, usually, or always much harder to care for than most children of a similar age, compared with only 31.6% of parents of noncomplex CSHCN and 8.3% of parents of non-CSHCN (P < .001). Parents of CMC had >2 times the odds of reporting that they were not handling the demands of raising children well compared with
parents of noncomplex CSHCN (aOR 2.4; 95% CI 1.3–4.5) and parents of non-CSHCN (aOR 7.1; 95% CI 3.9–12.9).

More than one-third (36.3%) of parents of CMC reported they did not know where to go for help in the community when they encountered difficulties. Parents of CMC had greater odds of reporting they did not know where to go for help compared with parents of noncomplex CSHCN (aOR 2.1; 95% CI 1.4–3.1) and parents of non-CSHCN (aOR 2.9; 95% CI 2.0–4.3). In the multivariate analysis (Table 3), demographic characteristics associated with increased odds of not knowing where to go for help included child of Black or African American race, child of Hispanic ethnicity, younger parent, Spanish speaking, and a lower household income. In a sensitivity analysis, we found that parents who reported they did not know where to go for help in their community had higher odds of reporting poor or fair mental health (aOR 2.1; 95% CI 1.7–2.6).

DISCUSSION
Our study shows that almost one-fifth of parents of CMC self-report poor or fair mental health. They are at the highest risk for suboptimal mental health compared with the 2 groups of parents of children without medical complexity. We also found that parents of CMC had limited knowledge of where to find help in the community. However, parents of CMC were more likely to report receiving emotional support from a health care provider, mental health professional, or advocacy group. Our work contributes to the existing literature that describes the psychosocial factors and challenges for parents of CMC to maintain emotional wellness. To our knowledge, this is the first study to describe the mental health of parents of CMC and their sources of support using a large national sample.

This study is novel in its design, comparing the mental health of parents of CMC with that of 2 other groups: parents of noncomplex CSHCN and parents of non-CSHCN. The presence of a CMC within a household stresses the emotional and physical resources of parents, siblings, and extended family. More than 75% of parents of CMC in our study stated they felt that their child was much harder to care for than other children and that they struggled to handle the demands of parenting. This study is important because parents of children with chronic conditions are vulnerable in many ways and may benefit from proactive screening for parental stress and efficient mechanisms for providing emotional support. Parents of CMC have higher levels of stress, marriage tensions, and financial difficulties and spend more hours coordinating and delivering medical care, which can disrupt functioning of the family unit. Parents of children who...
use medical technology (requiring assistance to function, such as a feeding tube, tracheostomy, or wheelchair) report limiting their social interactions, avoiding friends,27 and avoiding public areas because of embarrassment.22,28 For many parents of CMC, this social isolation likely impairs their emotional wellness.

A striking finding was that nearly one-third of parents of CMC reported they did not know where to find community help, and they had twice the odds of reporting this lack of knowledge compared with parents of noncomplex CSHCN. On the basis of the general wording of the survey item, the key drivers of this result are somewhat unclear. This finding may have been driven by parents of CMC who perceived an unmet need for specialized community supports, a lack of confidence in community organizations’ ability to accommodate their children, or a true lack of knowledge of community sources for help. In previous studies, authors have reported that parents of CMC rate community-based services, such as respite care, school and park accommodations, and home health, as insufficient.1 Peer and advocacy groups have been shown to decrease parents’ sense of anxiety and stress while creating connections to community supports and promoting parents’ well-being.29,30 Given that we found

### TABLE 3 Odds Ratio of Poor or Fair Mental Health and Not Knowing Where to Go for Help for Parents by Child’s Medical Complexity Status

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>aOR (95% CI) of Poor or Fair Parent Mental Health</th>
<th>aOR (95% CI) of Not Knowing Where to Go for Help in the Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMC versus noncomplex CSHCN</td>
<td>2.0 (1.1–3.8)*</td>
<td>2.1 (1.4–3.1)**</td>
</tr>
<tr>
<td>CMC versus non-CSHCN</td>
<td>4.6 (2.5–8.6)**</td>
<td>2.9 (2.0–4.3)**</td>
</tr>
<tr>
<td>** Covariates **</td>
<td></td>
<td></td>
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<tr>
<td>Child sex: female versus male</td>
<td>1.0 (0.8–1.2)</td>
<td>1.0 (0.9–1.1)</td>
</tr>
<tr>
<td>Child age, y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6–11 vs 0–5</td>
<td>1.0 (0.7–1.3)</td>
<td>1.1 (0.9–1.3)</td>
</tr>
<tr>
<td>12–17 vs 0–5</td>
<td>1.0 (0.8–1.3)</td>
<td>1.1 (0.8–1.3)</td>
</tr>
<tr>
<td>Child race</td>
<td></td>
<td></td>
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<tr>
<td>Black or African American versus white</td>
<td>1.0 (0.7–1.3)</td>
<td>1.7 (1.4–2.0)**</td>
</tr>
<tr>
<td>Other versus white</td>
<td>1.1 (0.8–1.4)</td>
<td>1.4 (1.1–1.6)**</td>
</tr>
<tr>
<td>Child ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic versus non-Hispanic</td>
<td>1.1 (0.8–1.5)</td>
<td>1.4 (1.1–1.6)**</td>
</tr>
<tr>
<td>Parent sex: female versus male</td>
<td>1.5 (1.1–1.9)**</td>
<td>1.1 (0.8–1.2)</td>
</tr>
<tr>
<td>Parent age in years, every 10 y</td>
<td>0.9 (0.8–1.0)*</td>
<td>0.8 (0.7–0.9)**</td>
</tr>
<tr>
<td>Parent’s highest grade of education</td>
<td></td>
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<tr>
<td>Some college or associate’s degree versus bachelor’s degree</td>
<td>1.2 (0.9–1.5)</td>
<td>1.3 (1.1–1.5)**</td>
</tr>
<tr>
<td>High school versus bachelor’s degree</td>
<td>1.4 (1.1–1.9)*</td>
<td>1.1 (0.9–1.4)</td>
</tr>
<tr>
<td>Less than high school versus bachelor’s degree</td>
<td>1.7 (1.1–2.6)**</td>
<td>1.1 (0.8–1.5)</td>
</tr>
<tr>
<td>Household language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spanish versus English</td>
<td>0.5 (0.3–0.8)*</td>
<td>1.5 (1.1–2.0)**</td>
</tr>
<tr>
<td>Other versus English</td>
<td>0.7 (0.4–1.1)</td>
<td>1.4 (1.1–1.9)*</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 parents, not married versus 2 parents, married</td>
<td>2.3 (1.6–3.3)**</td>
<td>1.4 (1.1–1.7)**</td>
</tr>
<tr>
<td>Single parent versus 2 parents, married</td>
<td>2.1 (1.6–2.6)**</td>
<td>1.2 (1.0–1.4)*</td>
</tr>
<tr>
<td>Other family type versus 2 parents, married</td>
<td>3.6 (1.6–8.0)**</td>
<td>1.5 (1.0–2.4)*</td>
</tr>
<tr>
<td>Household income by percentage of poverty level</td>
<td></td>
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</tr>
<tr>
<td>&lt;100% vs 400%+</td>
<td>2.3 (1.5–3.6)**</td>
<td>1.6 (1.2–2.0)**</td>
</tr>
<tr>
<td>100%–199% vs 400%+</td>
<td>2.1 (1.4–3.4)**</td>
<td>1.6 (1.3–2.0)**</td>
</tr>
<tr>
<td>200%–399% vs 400%+</td>
<td>1.6 (1.1–2.4)*</td>
<td>1.5 (1.2–1.7)**</td>
</tr>
<tr>
<td>Child insurance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private and public versus private</td>
<td>1.1 (0.7–1.8)</td>
<td>1.2 (0.9–1.5)</td>
</tr>
<tr>
<td>Public only versus private</td>
<td>1.1 (0.8–1.5)</td>
<td>1.2 (1.0–1.4)</td>
</tr>
<tr>
<td>Uninsured versus private</td>
<td>1.2 (0.8–1.9)</td>
<td>1.2 (0.9–1.6)</td>
</tr>
<tr>
<td>Unknown versus private</td>
<td>0.4 (0.2–1.0)</td>
<td>0.8 (0.4–1.3)</td>
</tr>
<tr>
<td>Region</td>
<td></td>
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<tr>
<td>Midwest versus East</td>
<td>1.5 (1.2–2.0)**</td>
<td>0.9 (0.8–1.1)</td>
</tr>
<tr>
<td>South versus East</td>
<td>1.2 (0.9–1.6)</td>
<td>1.0 (0.8–1.2)</td>
</tr>
<tr>
<td>West versus East</td>
<td>1.2 (0.9–1.7)</td>
<td>1.2 (1.0–1.4)</td>
</tr>
</tbody>
</table>

All data are weighted; logistic regression analyses are adjusted for child and family demographics, including child sex, child age, child race, child ethnicity, parent sex, parent age, parent education level, household language, family structure, household income by multiple imputation, type of health insurance, and geographic region.

**P < .01 *P < .05
evidence of a positive association between not knowing where to go for community help and poor or fair mental health, those parents who are disconnected from their communities may feel disempowered or isolated, which could influence their mental health and coping abilities. Future studies exploring this relationship may inform development of interventions to enhance parent wellness.

We also found that parents of CMC who were particularly at risk for not knowing where to find community help included those parents of children who were Black or African American, did not speak English, and lived in lower-income households. These groups are often part of marginalized communities, who may have difficulty accessing health care and community organizations. Interventions targeting marginalized communities through schools, community activities, or family support programs are crucial to ensure successful outreach and education for all families of CMC. Although our study did not reveal differences in parent mental health or knowledge of community help by child age, parents of adolescents are likely to require support that is different from that required by parents of younger children. An important research focus for future exploration is the period of transition from childhood to adulthood, when parental stress is heightened and targeted emotional and community support is essential. As policy makers and accountable care organizations design health system improvement efforts, they should evaluate how to best incorporate metrics related to child and family mental health and family functioning. Our findings may inform their efforts to benchmark parents’ experiences of support services. An increased research, clinical, and administrative focus on “whole child, whole family” metrics may drive improvement in family-centered outcomes and optimize value.

For parents of children across all medical complexity levels, our study highlights opportunities for health care systems to better support the emotional wellness of parents. Support for parents, including parents of CMC, may be best shared across the entire team in multiple settings, including mental health providers, advocacy groups, and peer support groups. Receiving support from these groups working in concert may help to promote parent mental wellness, as outlined in the expanded Chronic Care Model and Family Resilience Framework. Although our findings reveal that parents of CMC, including those who report suboptimal mental health, describe high levels of emotional support from mental health professionals and health care providers, they were still at highest risk for poor or fair mental health and for not knowing where to go in the community for help. This finding suggests that existing mechanisms are not sufficiently supporting the mental health needs of parents of CMC.

Although complex care programs have improved care coordination, access, and communication between parents and the health care team, no association has yet been found with improved parental mental health. In fact, as the health care system works to avoid hospitalizations and decrease lengths of stay, parents of CMC may feel increasingly stressed as they bear more responsibility for home care while their children are ill. Innovative clinical models that have begun targeting mental health as part of their programs have shown promising evidence that psychotherapy for parents of CMC improves their own mental health, child outcomes, and family functioning. There may be an opportunity to improve parent and family wellness by embedding mental health services for parents of CMC within inpatient and outpatient pediatric clinical systems.

For families caring for CMC, essential support and infrastructure can bolster good mental health and community integration, thereby sustaining meaningful relationships, positive life experiences, and personal fulfillment. However, further research is needed to investigate how to best connect parents of CMC with effective programming and resources that can promote parental resilience and family QoL in concert with optimizing health care use and outcomes of CMC. Specifically, we need to develop better ways to provide adequate home nursing, access to insurance and therapies, and respite care, all of which are reported as unmet needs by parents of CMC. Given that the health of CMC is intertwined with the family unit’s health and functioning, outcomes directly linked to parents should be evaluated from a population health perspective, with essential input from families of CMC.

This study has several limitations. Because data were obtained from a cross-sectional survey, causality could not be examined. Changes in the survey prevented comparisons of data from the 2016–2017 NSCH to data from earlier versions. All data were based on self-report and were therefore subject to recall and social desirability bias. Our evaluation of parent-perceived service needs for their children was limited by the survey items included in the NSCH and selected for this study. The depth of our analysis was
also limited by the general wording of some survey items, such as questions on parent mental health and knowledge of community sources for help. We acknowledge that the experiences of nonparent CMC caregivers are important to understand, but the small number of nonparent responses in the NSCH precluded examining these subgroups. With future iterations of the NSCH and a larger sample size, researchers may be able to compare parent and nonparent groups in future studies.

CONCLUSIONS
Among parents of children across all levels of child medical complexity, parents of CMC were at the highest risk for reporting poor or fair mental health, difficulty handling the demands of parenting, and not knowing where to find help in their community when they encountered difficulties. More parents of CMC than parents of children without medical complexity reported receiving emotional support from a health care provider, mental health professional, or advocacy group. Nonetheless, a substantial proportion of parents of CMC lacked this support. Our findings highlight that more research focused on parents of CMC is required to develop best practices and clinical programs that promote their emotional wellness and strengthen their connections to community resources. We found a critical need to design interventions to help families meet their emotional wellness needs. Such changes may improve the health and QoL for highly vulnerable parents and families of CMC, as well as CMC themselves, in the future.

ACKNOWLEDGMENTS
Constance D. Baldwin, PhD, professor of pediatrics (University of Rochester), offered valued mentorship and thoughtful revisions of the final manuscript.

ABBREVIATIONS
aOR: adjusted odds ratio
CI: confidence interval
CMC: child or children with medical complexity
CSHCN: children with special health care needs
non-CSHCN: children without special health care needs
NSCH: National Survey of Children’s Health
QoL: quality of life

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Pediatrics originally published online June 21, 2021;

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*Pediatrics* originally published online June 21, 2021;

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