https://doi.org/10.5664/jcsm.10064

JCSM | Journal of Clinical Sleep Medicine

SCIENTIFIC INVESTIGATIONS

Rates of diagnoses of sleep disorders in children with chronic medical conditions

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Study Objectives: This investigation examines sleep disorder (SD) diagnoses in a large population of children and adolescents with chronic medical conditions (CMCs). Little is known about SD diagnoses in this population. The large population used in this study allowed examination of SD rates by CMC type and demographics.

Methods: Data were from the Coordinated Health Care for Complex Kids (CHECK) project designed for Medicaid-funded children and adolescents with at least 1 CMC from a large metropolitan area. The study population (n = 16,609) was limited to children and adolescents, 0 to 18 years of age. SD and CMC diagnoses were obtained from Medicaid claims data.

Results: Fourteen percent of the population (mean age of 9.1 years [standard deviation = 5.2]; 35.8% African American; 56.4% male; 77 with more than 1 CMC) received a sleep disorder diagnosis. The most frequent diagnosis was sleep-disordered breathing (11.2%), followed by nocturnal enuresis (1.2%) and insomnia (1%). SDs were diagnosed more frequently in those with multiple CMCs than in those with 1 CMC (19.7% vs 5.8%; $P < .001$). Insomnia rates in Hispanic/Latinx (1.2%) and African American (0.8%) children and adolescents were significantly lower (both $P < .001$) than in Caucasians (3.5%). Odds of receiving a sleep diagnosis varied among CMCs.

Conclusions: Our analysis of Medicaid claims data of a large urban cohort offers detailed information about the rates of sleep diagnoses and suggests underdiagnosis of SDs in this vulnerable, high-risk, primarily ethnic minority population. Underrecognition of sleep disorders has short- and long-term health and economic consequences. Study results may help clinicians implement appropriate SD screening and management for children and adolescents with CMCs.

Keywords: chronic medical conditions, rates of sleep diagnoses, diagnosis of sleep disorders, sleep in high-risk children

Citation: Adavadkar PA, Pappalardo AA, Glassgow AE, et al. Rates of diagnoses of sleep disorders in children with chronic medical conditions. *J Clin Sleep Med*. 2022;18(8):2001–2007.

BRIEF SUMMARY

Current Knowledge/Study Rationale: Sleep disorders are commonly underdiagnosed in general pediatric population by primary care providers. Though sleep disorders are more prevalent and may worsen health outcomes in children with chronic medical conditions the data about the rates of diagnosis of sleep disorders in this high-risk population are not clear.

Study Impact: In this study the rates of sleep diagnoses assigned by varied pediatric providers were systematically examined in a large cohort of high-risk children with chronic medical conditions in a tertiary care center. The findings suggest underdiagnosis of sleep disorders in this high-risk group. Also, the rates among different groups by age, number, and types of chronic medical conditions were examined.

INTRODUCTION

Sleep problems are more common and persistent in children and adolescents with chronic medical conditions (CMCs) compared to healthy peers.[1–4] Research has shown that sleep problems are often underrecognized,[1,2] underdocumented,[5] and underdiagnosed[3] in the general pediatric population, but similar data in high-risk children and adolescents with medical complexity are limited. Untreated sleep disorders are associated with poor health outcomes and high health care utilization and cost.[6–8] Treatment of sleep disorders has been shown to improve health outcomes[9–11] and quality of life[12] and to reduce health care utilization and cost.[13] Because health care utilization and costs are disproportionately higher in children and adolescents with CMCs[3,14] it is important to carefully examine how frequently sleep disorders are diagnosed in this high-risk pediatric population.

This study population is composed of children and adolescents with high medical complexity who received care from not only primary care providers but also from pediatric subspecialists, emergency medicine physicians, and in-patient providers. Therefore, the study offers information about the practice of diagnosing sleep disorders by a broad range of providers. Because the prevalence and severity of sleep disorders in this age group varies by epidemiologic factors, we examined rates of sleep diagnoses by age and race/ethnicity. We also compared the rates of sleep diagnosis between children and with 1 CMC and those having multiple CMCs because health

care utilization and cost are significantly higher for those with multiple CMCs.[19]

METHODS

Study population

Study data were obtained from the Coordinated Health Care for Complex Kids (CHECK) program funded under a Centers for Disease Control and Prevention Healthcare Innovation Award.[15] Persons eligible for enrollment in this program were Medicaid beneficiaries 25 years of age or less residing in Cook County and having one or more CMCs. Participants who enrolled in the CHECK project between 2014 and 2018 were studied. Medicaid claims data were used to select CHECK enrollees with *International Classification of Diseases, Ninth Revision* (ICD-9), or/and *International Classification of Diseases, Tenth Revision, Clinical Modification* (ICD-10-CM), codes for attention-deficit/hyperactivity disorder (ADHD), asthma, obesity and other metabolic disorders, type 1 or type 2 diabetes, premature birth, seizure disorder, sickle cell disease, or some other, mostly neurological, chronic disease.[16,17] Referrals came from the State of Illinois Department of Healthcare and Family Services (ie, Medicaid), Medicaid Managed Care Organizations, the University of Illinois at Chicago Hospitals, or by self-referral.[18] Participants in this study were 0 to 18 years of age.

We extracted Illinois Medicaid claims data for each participant. ICD-10-CM diagnostic codes were used to determine sleep disorders and CMCs. The older *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM), codes were converted to ICD-10-CM codes. Few siblings of the participants were also included in the CHECK project even if they did not have a CMC. We identified and excluded participants without a CMC (n = 1,192) from our sample. The top 5 most prevalent CMC groups were used for analysis. We used the Chronic Clinical Indicator tool developed by the Healthcare Cost and Utilization Project to identify participants with chronic conditions (https://www.hcup-us.ahrq.gov).

Measures

For data analyses the population was divided into 5 different subgroups based on age: infants and toddlers (0–2 years), preschool (3–5 years), elementary school (6–10 years), middle school (11–13 years), and high school (14–18 years). The population was also categorized by the 5 most prevalent CMC groups: asthma, other respiratory diseases, obesity and other endocrine/metabolic disorders, developmental disorders, and ADHD. We also compared children with 1 CMC to children with multiple CMCs.

Sleep diagnoses related to breathing difficulty including snoring, sleep apnea, and combined snoring and sleep apnea were grouped as sleep-disordered breathing (SDB). Diagnoses of periodic limb movement disorder and restless legs syndrome were grouped as sleep-related movement disorders. Sleepwalking, confused arousal, sleep terrors, nightmares, and other parasomnias were grouped as parasomnia disorders.

Data analysis

Chi-square tests and univariate and multivariable logistic regressions were performed to test associations between race/ethnicity and CMC with sleep diagnoses and to produce confidence intervals. P values < .05 were considered statistically significant. Analyses were performed using R Version 3.6.0. Each participant's information was deidentified. The University of Illinois at Chicago Institutional Review Board approval for secondary analyses of the CHECK data is covered by Protocol No. 2016-0235.

RESULTS

Demographic characteristics

The study population included 16,609 young people with a mean age of 9.08 years (standard deviation: 5.3 years; range: 0–18 years). The cohort mostly consisted of children of African American (35.8%) and Hispanic/Latinx (20.1%) ethnicities. Though ethnic information was unknown in about 40% of the population, a review of the referral areas (https://chicagohealthatlas.org/) showed that the areas were predominantly Black and Latinx. The participants with unknown race were coded as having race "unknown" and included for the analyses. Demographic information is provided in **Table 1**.

International Classification of Diseases, Tenth Revision (ICD-10), diagnostic codes for the various sleep diagnoses and their frequencies in this population are shown in **Table 2**. Fourteen percent of the children and adolescents received a sleep disorder diagnosis. SDB was the most frequently diagnosed sleep disorder among all age groups. The rate of a SDB diagnosis was highest in the 0–2-year age group (n = 371, [17.3%]) and decreased progressively with age, with the lowest rate in the 14–18-year age group (n = 273, [6.4%]). Conversely, an insomnia diagnosis was most prevalent in the 14–18-year age group (n = 97, [2.3%]) and the rate progressively decreased in younger children with the lowest rate in the 0–2-year age group (n = 6, [0.3%]).

Comparative prevalence of sleep disorders in current and past studies

Table 3 shows a comparison of the prevalence of sleep disorder diagnoses in this study population compared to other published studies. Sleep disorders were diagnosed more frequently in our high-risk cohort compared to those reported in Meltzer et al study[3] of a healthier population. However, the rates of most of the sleep diagnoses in our cohort were much lower than epidemiologic estimates of the general pediatric population.

Odds of receiving sleep diagnoses by CMC

For these analyses, the population was divided into the 5 most prevalent CMC groups: asthma (n = 12,198), other respiratory diseases (n = 5,234), overweight/obesity and other endocrine/metabolic disorders (n = 3,850), developmental disorders (n = 3,729), and ADHD (n = 1,336). Univariate logistic regression analyses were performed to estimate the odds of having a specific sleep disorder given a CMC category. **Figure 1** shows the

Table 1—Demographic characteristics of participants.

	Values
Total, n	16,609
Age in years, mean (SD)	9.08 (5.3)
Age categories in years, n (%)	
0–2	2,142 (12.9)
3–5	2,886 (17.4)
6–10	4,802 (28.9)
11–13	2,532 (15.2)
14–18	4,247 (25.6)
Male sex, n (%)	9,372 (56.4)
Race/ethnicity, n (%)	
Caucasian	310 (1.9)
African American	5,949 (35.8)
Hispanic/Latinx	3,339 (20.1)
Other (includes Asian, American Indian, Hawaiian)	101 (0.6)
Two or more	275 (1.7)
Unknown/missing	6,635 (39.9)

SD = standard deviation.

odds of receiving a specific sleep diagnosis in each CMC group compared with the rest of the cohort.

The ADHD group had elevated odds of receiving a sleep diagnosis compared to the rest of the cohort. For example, children in the ADHD group were almost 7 times more likely to receive a diagnosis of insomnia (odds ratio [OR] = 6.9; confidence interval [CI]: 5.0–9.5; $P < .001$) and 6 times more likely to receive a diagnosis of circadian rhythm sleep disorder diagnosis (OR = 6.1 [CI: 2.1–13.7], $P < .001$) compared to the rest of the cohort.

Similarly, children in the overweight/metabolic disorders group were 4 times more likely to receive a diagnosis of sleep-related movement disorder (OR = 4.4 [CI: 2.5–7.8], $P < .001$) compared to the rest of the cohort. Odds of receiving the diagnosis of circadian rhythm sleep disorders were 3 times higher in the developmental disorder group than in the rest of the cohort (CI: 1.4–6.4, $P = .008$).

Compared to the rest of the cohort, those in the other respiratory disorders group had higher odds of receiving the diagnoses of SDB (OR = 2.0 [CI: 1.8–2.2], $P < .001$), insomnia (OR = 1.9 [1.4–2.6], $P < .001$), and sleep-related movement disorders (OR = 3.8 [CI: 2.1–6.7], $P < .001$). For children in the asthma group the odds of receiving a sleep diagnosis did not differ significantly from the rest of the cohort except for nocturnal enuresis (OR = 0.7 [CI: 0.6–0.9], $P < .05$) and other sleep disorders (OR = 0.7 [CI: 0.6–0.9], $P < .05$), which were in fact lower.

Table 2—ICD-10 codes and prevalence of sleep disorder diagnoses, overall and by age categories.

ICD-10 Diagnostic Codes	Sleep Disorder	Total	0–2 years	3–5 years	6–10 years	11–13 years	14–18 years
		n = 16,609	n = 2,142	n = 2,886	n = 4,802	n = 2,532	n = 4,247
780.51, 780.53, 780.57, 27.20, 327.1, 327.23, 327.26, 786.09, 786.03, 786.09, 786.03	Sleep-disordered breathing	1,852 (11)	371 (17.3)	452 (15.7)	580 (12.1)	176 (7.0)	273 (6.4)
327.01, 327.02, 327.09, 780.51, 780.52	Insomnia	169 (1)	6 (0.3)	10 (0.3)	27 (0.6)	29 (1.1)	97 (2.3)
788.36, 788.30	Nocturnal enuresis	205 (1.2)	7 (0.3)	40 (1.4)	107 (2.2)	27 (1.1)	24 (0.6)
327.40, 327.41, 327.42, 327.43, 327.44, 327.49	Parasomnias	48 (0.3)	6 (0.3)	12 (0.4)	24 (0.5)	3 (0.1)	3 (0.1)
780.58, 327.51, 333.94	Sleep-related movement disorders	49 (0.3)	2 (0.1)	8 (0.3)	28 (0.6)	5 (0.2)	6 (0.1)
327.31, 327.30, 327.39, 307.45, 780.55	Circadian rhythm sleep disorders	26 (0.2)	1 (0.0)	3 (0.1)	4 (0.1)	4 (0.2)	14 (0.3)
307.43, 327.10, 327.11, 327.12, 327.14, 780.54	Hypersomnia	20 (0.1)	0 (0.0)	2 (0.1)	7 (0.1)	6 (0.2)	5 (0.1)
347.00, 347.10	Narcolepsy with cataplexy	2 (0.01)	0 (0.0)	0 (0.0)	1 (0.0)	0 (0.0)	1 (0.0)
327.8, 307.49, 307.47, 780.50, 780.58, 780.59	Other sleep disorders/ unspecified	347 (2.1)	37 (1.7)	74 (2.6)	112 (2.3)	42 (1.7)	82 (1.9)

Values are presented as n (%). ICD-10 = *International Classification of Diseases, Tenth Revision*.

Table 3—Comparative prevalence of sleep disorders in current and past studies.

Sleep Disorder Grouping	Rates of Diagnosis Based on Epidemiologic Studies	Rates of Diagnosis by Pediatricians during Well-Child Visits[3]	Rates in Current Study (Total Participants, n = 16,609)
Sleep-disordered breathing	1–4% for obstructive sleep apnea, 5–27% for snoring[29–32]	1.04%	11%
Insomnia	10–30%[29,33,34]	0.05%	1.0%
Nocturnal enuresis	15–20% (5 y), 1–2% (≥ 15 y)[35,36]	1.2% (≥ 4 y)	1.2%
Parasomnias	14–37%[29,37,38]	0.05%	0.3%
Sleep-related movement disorders	2–8%[39–41]	0.02%	0.3%
Circadian rhythm sleep disorders	5–10%[42]	0.005%	0.2%
Hypersomnia	Unknown	0.004%	0.1%
Narcolepsy with cataplexy	Unknown	0.003%	0.0012%

Sleep diagnoses were significantly more prevalent for children and adolescents with multiple CMCs compared to those with only 1 CMC (**Table 4**). The prevalence of SDB diagnosis was more than twice higher for children and adolescents with multiple CMCs (n = 1652, [13%]) compared to those with 1 CMC (n = 200 [5.2%], $P < .001$). Sleep disorder diagnoses were mostly assigned in the multiple CMC group.

Sleep diagnoses by race/ethnicity

Insomnia was diagnosed most frequently in Caucasian participants (n = 11, 3.5%) and least frequently in African American participants (n = 45, 0.8%). Univariate regression analyses showed statistically significant differences in insomnia diagnosis rates among races. Odds of receiving an insomnia diagnosis for African American participants (OR = 0.21 [95% CI:

Figure 1—Odds ratios and 95% confidence intervals for six sleep disorders by five chronic medical conditions.

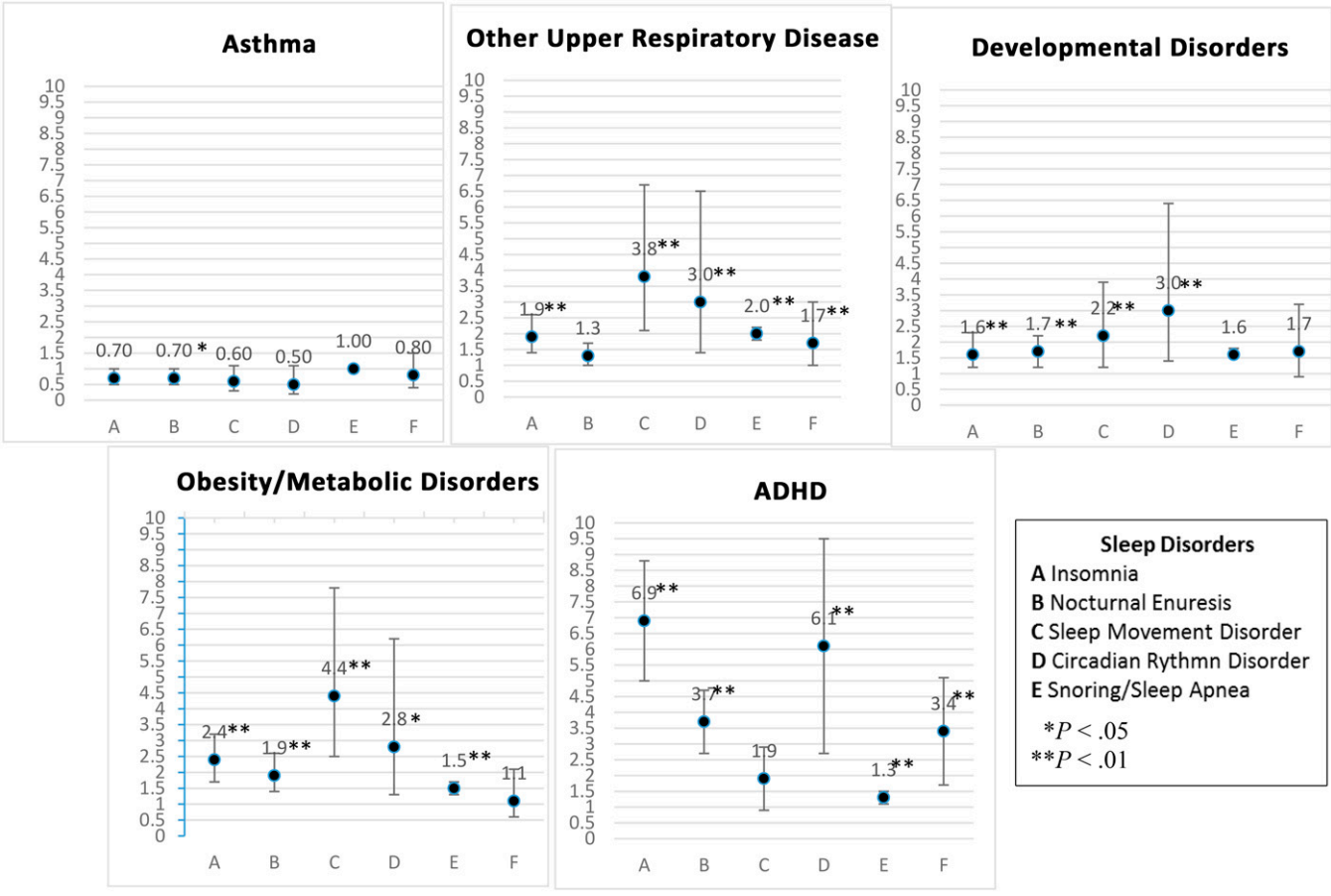

Table 4—Prevalence of sleep disorders by number of chronic medical conditions (CMCs).

Sleep Disorder, n (%)	One CMC n = 3,864 (23%)	Multiple CMCs n = 12,745 (77%)	*P*
Sleep-disordered breathing	200 (5.2%)	1652 (13.0%)	<.001
Insomnia	3 (0.1%)	166 (1.3%)	<.001
Nocturnal enuresis	2 (0.1%)	203 (1.6%)	<.001
Parasomnia	0 (0%)	48 (0.4%)	<.001
Sleep-related movement disorder	0 (0%)	49 (0.4%)	<.001
Circadian rhythm sleep disorders	0 (0%)	26 (0.2%)	.010
Hypersomnia	0 (0%)	20 (0.2%)	.028
Narcolepsy with cataplexy	0 (0%)	2 (0.0%)	1.000
Other sleep disorders	14 (0.4%)	333 (2.6%)	<.001

0.11–0.43]; $P < .001$) and Hispanic participants (OR = 0.33 [95% CI: 0.17–0.68]; $P = 0.001$) were significantly lower compared with Caucasian participants. No significant differences were noted among racial/ethnic groups for other sleep disorders.

DISCUSSION

This study provides information about how frequently sleep disorders are diagnosed by pediatricians who care for high-risk participants and how sleep diagnosis rates are related to various demographic factors and chronic medical conditions. **Table 3** shows that sleep disorders were diagnosed more frequently in this study's high-risk population compared to those reported in a study of a healthier population,[3] yet they are lower than those observed in epidemiological studies (see **Table 3**). While the difference in this study population compared to the healthier group might readily be explained by the presence of high-risk participants in this study, the difference compared to the epidemiological studies has yet to be explained.

One explanation for the latter difference is that sleep disorders are underdiagnosed in participants with chronic medical disorders. There are a few reasons why this explanation is plausible. First, this may indicate that a sleep knowledge gap exists in physician training.[14,20] Another possibility is that diagnosing a sleep disorder is a secondary concern for participants who are being treated for acute or specialized care.

Other factors may come into play to explain the discrepancy between the higher epidemiologic estimates of the prevalence in school-aged and adolescent participants[21] and the highest rate of SDB diagnosis in younger children. These could be because caregivers of infants and toddlers are more likely to bring up sleep problems during health visits compared to those of older participants.[1,2,22] Sleep problems in infants and toddlers are mostly behavioral in nature; therefore, any parental report of snoring, breathing difficulties or other symptoms of SDB in this age group makes diagnosing SDB more likely.[23] The older participants may sleep alone and not be observed as closely, resulting in parental underreporting of sleep concerns for this group.[24] This pattern suggests the importance of sleep-disorder screening for older pediatric participants.

The rates of insomnia diagnosis varied among different ethnic groups. Although children with ethnic minority backgrounds and lower socioeconomic status have poorer sleep quality compared to the wealthier White population,[24–28] in this population insomnia was diagnosed less frequently in African American and Hispanic/Latinx participants compared to Caucasian participants. This is likely due to the knowledge or awareness gap among parents highlighting the importance of providers' proactive approach in evaluating and diagnosing sleep problems in participants of the ethnic minority.

Strengths and limitations

A major strength of this study is that a study population of more than 16,000 pediatric participants with chronic health problems allowed detailed analysis of the prevalence of sleep diagnoses by various demographic factors and CMCs. A second strength is that the study is not limited to primary care pediatricians but provides an estimate of the practice of diagnosing sleep disorders by varied providers. Nevertheless, there are limitations that are worth noting. First, diagnoses were based only on ICD-9 and ICD-10 codes present in the Medicaid claims data and no attempt to validate this information with chart reviews was conducted. Sleep medication data or other clinical data was not available. It may be the case that providers documented a sleep disorder in a participant's medical record but deemed it unnecessary to assign a sleep disorder diagnosis. Second, types of providers and clinical settings were not identified, making it impossible to compare rates of SD diagnoses by these characteristics. Third, participants in this study were publicly insured racial/ethnic minorities living in an urban setting. Thus, generalization to the general pediatric population is limited. Finally, sizes of certain groups were small, and their results should be interpreted with caution.

CONCLUSIONS

The data about the rates of diagnoses of sleep disorders in the high-risk cohort are limited. Our analyses of Medicaid claims

data provide the detailed information about how frequently sleep disorders are diagnosed in a large cohort of children with chronic illnesses. The rates of sleep diagnoses varied significantly by type and number of CMCs and by demographic factors. Sleep disorders appear to be underdiagnosed in this high-risk vulnerable population which may have short- and long-term health and economic consequences. Results of this study may help clinicians implement appropriate screening and diagnosis of sleep disorders in children with chronic illnesses.

ABBREVIATIONS

ADHD, attention-deficit/hyperactivity disorder
CHECK, Coordinated Healthcare for Complex Kids
CI, confidence interval
CMC, chronic medical condition
ICD, *International Classification of Diseases*
OR, odds ratio
SDB, sleep-disordered breathing

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ACKNOWLEDGMENTS

The authors gratefully acknowledge the editorial assistance of Kenneth Rasinski, PhD in the preparation of this manuscript. Author contributions: Dr. Adavadkar is the principal investigator of this research study. He conceptualized the study, collected, and analyzed the data, led the research effort, and wrote the primary manuscript draft. Drs. Martin, Zhang, Glassgow, Lee, and Pappalardo participated in the drafting, reviewing/editing, and revising the manuscript. Dr. Schwartz performed statistical analysis of the data in addition to reviewing/editing the manuscript.

SUBMISSION & CORRESPONDENCE INFORMATION

Submitted for publication November 30, 2021
Submitted in final revised form April 13, 2022
Accepted for publication April 13, 2022
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DISCLOSURE STATEMENT

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work. The authors report no conflicts of interest.