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Race-based disparities in access to surgical palliation for hypoplastic left heart syndrome

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ABSTRACT

Background: Racial disparities in outcomes have been shown to persist in many operative specialties, including the management of congenital heart disease. Using a demographic-adjusted methodology, we examined whether patient race influenced access to high-performing centers for the operative management of hypoplastic left heart syndrome.
Methods: The 2005–2017 National Inpatient Sample was queried to identify all pediatric (≤5 years) hospitalizations with an operation for hypoplastic left heart syndrome. A racial disparity index was generated for each hospital and defined as the proportion of White patients receiving operative management for hypoplastic left heart syndrome divided by the proportion of White patients admitted for respiratory failure. This methodology quantified hospital-level racial variation while adjusting for the local racial makeup of each center.
Results: Of the 17,275 patients who met inclusion criteria, 64.1% were managed at high-volume centers. Patients at high-volume centers had a similar distribution of operative type, age, and burden of comorbidities. The mean racial disparity index steadily grew from 1.06 at the lowest volume decile of operative volume to 1.51 at the highest, indicating an increasing proportion of White patients as volume increased. Using risk-adjusted analysis, each decile increase in hospital volume was associated with a 14% relative reduction in odds of mortality and a 0.06 increase in predicted racial disparity index. Increasing volume was further associated with reduced odds of non-home discharge but did not alter resource utilization.
Conclusion: We demonstrate that high-volume centers disproportionally serve White patients and have superior clinical outcomes compared to low-volume centers. This study highlights the critical importance of equitable access to expert care for high-risk conditions such as hypoplastic left heart syndrome.

Introduction

Hypoplastic left heart syndrome (HLHS) is characterized by severe underdevelopment of the left ventricle, which typically includes systemic outflow tract obstruction or atresia.[1] Without early intervention, the spectrum of HLHS is uniformly fatal.[2] Despite improvements in the survival of children with many forms of congenital heart disease (CHD), early mortality after surgical palliation for HLHS remains in excess of 10%.[1,3,4] Over the past 30 years, however, mortality has decreased significantly, with several factors including centralization of care and advances in longitudinal medical and surgical management cited as potential reasons.[3,5] However, definitive racial disparities in outcomes persist, w ith Black and Hispanic patients suffering higher mortality rates following operations in CHD compared to Whites.[6–11] The

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causes for such observed disparities remain unclear and are likely multifactorial.

While a previously demonstrated positive volume-outcome relationship in palliative operations for HLHS exists,[12,13] the impact of race on access to expert centers remains ill-defined. The potential issue of disparities in access is further highlighted by research indicating that non-White minorities on average live closer to high-volume centers for surgical and medical specialties but receive less care at those hospitals compared to Whites.[14] Identification of factors influencing access to expert centers is imperative in addressing socioeconomic determinants of care in patients with CHD. Therefore, we used a nationally representative database to examine race-based disparities in access to high-quality care for the surgical treatment for HLHS. We hypothesized non-White race to be independently associated with reduced odds of receiving such operations at high-volume centers.

Material and methods

The 2005–2017 National Inpatient Sample (NIS) was queried to identify all pediatric (≤5 years) hospitalizations with the diagnosis of HLHS. As part of the Healthcare Costs and Utilization Project (HCUP), the NIS is the largest publicly available all-payer inpatient database in the United States and provides accurate estimates for 97% of all hospitalizations.[15] In 2012, the NIS switched from sampling all discharges at 20% of hospitals to 20% of records at all participating centers. Accounting for sampling differences and clustering, HCUP provides trend and discharge weights to generate national estimates for all inpatient hospitalizations. All analyses used survey-weighting methodology to estimate a national sample. We have previously demonstrated concordance between the NIS and Kids' Inpatient Database with the NIS, providing annual data rather than every 3 years.[16]

Patient and hospital characteristics were tabulated using the International Classification of Diseases, Ninth and Tenth Revision (ICD 9, ICD 10) diagnostic and procedural codes, and the NIS data dictionary. Hospitalizations with procedural codes for Norwood, Glenn, or Fontan operations were included (Supplementary Table S1), while those with missing data for age, race, insurance status, hospital identifier, or mortality were excluded (0.2%; Supplementary Figure S1). The Charlson Comorbidity Index,[17] a previously validated composite of 19 conditions (scored 1–6), was used to numerically estimate the burden of chronic conditions. Non-White race included those who self-identified as Black, Hispanic, Asian, or other.

To adjust for local racial demographics, we created a racial disparity index (RDI) for each hospital based on normalizing methodology:

$$RDI = \frac{\textit{Proportion of White patients receiving operations for HLHS}}{\textit{Proprotion of White patients admitted for respiratory failure}}$$

This index compares the racial demographics of patients undergoing HLHS operations to the composition of those of a similar age distribution admitted for an urgent condition.[18,19] The urgency of respiratory failure likely indicates that patients are admitted without referral to high-volume or low-volume centers. Therefore, the index indicates a racial referral bias at each center, as it normalized to the racial makeup of the surrounding population.[20–24] An index exceeding unity (RDI >1) would indicate a higher proportion of White patients receiving operations for HLHS compared to in the surrounding area. Hospitals were stratified into deciles of annual operative HLHS case volume. With the cutoff chosen based on the inflection point of annual operative volume (Supplementary Figure S2), facilities were considered high-volume centers (HVC) if in the top 3 deciles and otherwise classified as low-volume center (LVC). The lowest 2 deciles were omitted due to HCUP reporting guidelines ($n < 10$).[25]

The primary outcome of interest was the relationship between RDI and hospital volume. The secondary outcomes were the association of hospital volume with clinical and financial outcomes for HLHS. Hospitalization costs were derived by applying hospital specific cost-to-charge ratios to total charges and inflation-adjusted to the 2017 Personal Health Care–Hospital Care Index.[26]

Categorical and continuous variables are reported as frequencies (%) and means with standard deviation (SD), respectively. Costs, which demonstrated a skewed distribution, were reported as medians with interquartile ranges (IQR). The Pearson χ^2 and the adjusted Wald tests were used to analyze categorical and continuous variables, respectively. Significance of linear trends was assessed using a rank-based nonparametric test developed by Cuzick.[27] The Stata "margins" command was used to render the adjusted marginal effect of RDI and operative volume on various outcomes.

Multivariable linear and logistic regression models were developed to adjust for RDI as well as clinically relevant patient and hospital characteristics. Covariates were selected using the Elastic Net method, which selects variables for inclusion using a penalized least-squares methodology while accounting for collinearity.[28] The study cohort was initially divided into equal (1:1) derivation and validation subsets, while variables were selected using 3 iterations of 10-fold cross-validation over alpha values (.5, .75, 1). Models were then evaluated using an area under the receiver operating characteristic curve (C-statistic) and Akaike and Bayesian information criteria. The postestimation model for mortality across volume deciles was verified with the application of restricted cubic splines over 3 knots to ensure optimal fit (Supplementary Figure S3). Selected variables for risk-adjusted RDI included age, sex, insurance status, income quartile, Charlson Comorbidity Score, operative type, hospital teaching status, hospital region, hospital operative volume, anemia, kidney disease, coagulopathy, and calendar year. Models for secondary outcomes adjusted for RDI, age, sex, insurance status, Charlson Comorbidity Score, operative type, hospital teaching status, hospital region, hospital operative volume, anemia, kidney disease, coagulopathy, and calendar year. Regression outcomes are reported as adjusted odds ratios (AOR) for dichotomous variables and beta coefficients (β) for continuous variables, both with 95% confidence intervals (95% CI). All statistical analyses were performed using Stata version 16.[29] This study was deemed exempt from full review by the Institutional Review Board at the University of California, Los Angeles.

Results

Baseline characteristics

Of an estimated 17,275 hospitalizations meeting inclusion criteria, 64.1% occurred at HVC (encompassing 123 hospitals), with a mean annual operative volume of 33.4 (SD: 29.5) cases per year. Over the study period, there was no significant change in the mean RDI (nptrend = 0.60; Supplementary Figure S4). Compared to LVC, patients at HVC had a similar distribution of age and burden of comorbidities as described by the Charlson Index (Table I). Of note, proportions of operative staging: Norwood, Glenn, and Fontan did not differ significantly between hospital volume groups ($P = .87$). However, patients at HVC were more likely to be White (48.5 vs 43.8%, $P < .001$), belong to the highest income quartile (21.8 vs 15.0%, $P = .01$), and be privately insured (46.8 vs 38.3%, $P = .03$). Further, HVC were more frequently in the Northeast than LVC (23.2 vs 7.9%, $P = .03$). While the mean RDI for all hospitals was 1.3 (SD:

Table I
Demographic, clinical, and hospital characteristics by volume status

	Low-volume center (6,198)	High-volume center (11,077)	P value
RDI, SD	1.2 (0.5)	1.4 (0.5)	.001
Demographics (%)			
Neonate	34.1	30.9	.04
1 year old	40.6	44.6	
2 years old	10.8	13.8	
3 years old	7.9	7.2	
4 years old	4.8	2.8	
5 years old	1.7	0.8	
Female (%)	34.1	38.5	.02
Charlson Comorbidity score, SD	0.3 (0.6)	0.3 (0.6)	.31
Procedure (%)			.87
Norwood	38.4	37.7	
Glenn	33.4	34.6	
Fontan	28.2	27.8	
Comorbidities (%)			
Congenital kidney disorder	3.5	2.7	.24
Congenital lung disorder	3.4	2.8	.37
Asthma	1.6	0.8	.04
Congenital nervous system disorder	1.8	1.3	.29
Chromosomal abnormality	2.7	2.9	.78
Pulmonary hypertension	5.1	3.2	.01
Hypertension	5.5	10.3	<.001
Coagulopathy	7.9	6.6	.24
Preterm birth	2.7	2.3	.53
Race (%)			<.001
White	43.8	48.5	
Non-White	56.2	51.5	
Median household income (%)			.01
0–25th percentile	30.7	25.5	
25–50th percentile	28.2	27.2	
50–75th percentile	26.2	25.4	
75–100th percentile	15.0	21.8	
Insurance status (%)			.03
Private	38.3	46.8	
Government funded	53.1	46.5	
Other/Uninsured	8.6	6.7	
Hospital region (%)			.03
Northeast	7.9	23.2	
Midwest	32.2	17.5	
South	37.1	36.9	
West	22.8	22.2	
Hospital teaching status (%)			.01
Rural	0.0	0.0	
Urban non-teaching	5.0	0.9	
Urban teaching	95.0	99.1	

RDI, Racial Disparity Index; *SD*, standard deviation.

0.5), HVC had a higher mean RDI (1.4 ± 0.5) compared to LVC (1.2 ± 0.5, $P < .001$). The mean RDI steadily increased from 1.06 ± 0.5 at the lowest volume decile to 1.51 ± 0.6 at the highest ($P < .001$; Figure 1).

Impact of operative volume on unadjusted outcomes

On univariate comparison, a reduction in index mortality was noted with increasing volume, from 10.5% mortality at LVC to 5.7% at HVC ($P < .001$). With operative volume stratified into deciles, mortality rates exhibited an inflection point above and below the eighth decile (Figure 1). Both operative volume groups had similar rates of non-home discharge, adjusted costs, and postoperative length of stay (all $P > .05$; Table II). Similarly, no differences in complication rates were apparent, except for that noted in the requirement for extracorporeal life support, as shown in Table II.

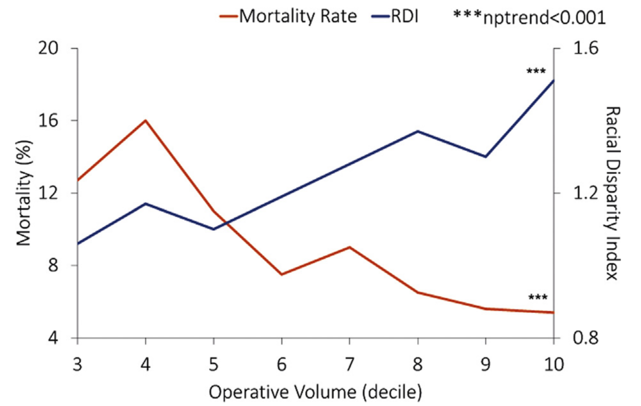

Figure 1. Mortality and racial disparity index by volume decile (*RDI*, Racial Disparity Index; note: lowest 2 deciles dropped due to Healthcare Cost and Utilization Project guidelines, nptrend: nonparametric test for trend).

Relationship between RDI and operative volume

After adjusting for patient and hospital factors, RDI exhibited a high correlation with hospital operative volume as shown in Figure 2. Across volume deciles, RDI exhibited an incremental $\beta = .06$ increase in RDI per decile (95% CI: 0.03–0.09, $P < .001$; Figure 2).

Operative volume outcomes relationship

On risk-adjusted analysis, each decile increase in hospital volume was associated with a 14% decrement in odds of mortality (AOR: 0.86, 95% CI: 0.81–0.91, $P < .001$; Figure 3). Although increasing volume was associated with reduced odds of non-home discharge as shown in Figure 4 (AOR: 0.95/decile, 95% CI: 0.91–0.99, $P = .02$; Figure 3), it did not impact postoperative length of stay or adjusted costs ($P > .05$; Table III). A multivariable logistic subset analysis was performed of racial variation within each hospital volume cohort.

Compared to LVC, HVC status was associated with reductions in odds of mortality for both White (AOR: 0.57, 95% CI: 0.38–0.86, $P = .007$) and non-White patients (0.63, 95% CI: 0.41–0.96, $P = .03$; Figure 4). Within LVC, non-White patients were not at significantly increased risk of mortality (AOR: 1.24, 95% CI: 0.83–1.86, $P = .30$) with Whites as reference.

Discussion

Over the past several decades, surgical management for children with HLHS has grown increasingly centralized with concomitant reductions in mortality. However, racial disparities are noted in long-term outcomes across congenital heart diseases, including HLHS.[30] The present work used a nationally representative cohort of nearly 18,000 patients undergoing surgical treatment for HLHS and examined access of non-White minorities to high-volume centers. We made several important observations: (1) increasing operative volume was associated with reduced mortality but unchanged resource utilization; (2) high-volume centers were more likely to serve White patients, as evidenced by higher RDI in the top volume deciles; (3) the association of non-White race and increased mortality disappeared at high-performing centers, suggesting that access to high-volume centers may play a role in the observed differences in racial outcomes. Several of these findings warrant further discussion.

Table II
Outcomes of operative management for hypoplastic left heart syndrome by volume status

Outcome	Low-volume center (6,198)	High-volume center (11,077)	P value
Complications (%)			
Acute ischemic stroke	2.1	2.0	.80
Seizure	3.4	3.5	.92
Infection	8.1	8.6	.68
Hemorrhage	13.7	12.9	.56
Postoperative extracorporeal life support*	8.0	5.1	.001
Postoperative prolonged mechanical ventilation	34.9	33.5	.67
Gastrostomy	5.1	4.6	.62
Discharge disposition (%)			
Mortality	10.5	5.7	<.001
Routine discharge	72.0	75.0	.37
Home health discharge	15.0	16.1	.71
Skilled nursing facility	2.5	2.8	.65
Cost ($1,000 USD, median, IQR)	148.8 (51.7–181.2)	147.3 (51.8–165.2)	.89
Postoperative length of stay (days, mean, SD)	24.2 (28.6)	21.8 (25.5)	.12
Prolonged length of stay (>20 days, %)	46.5	39.7	.08

IQR, interquartile range; *SD*, standard deviation.
* Only capable centers considered.

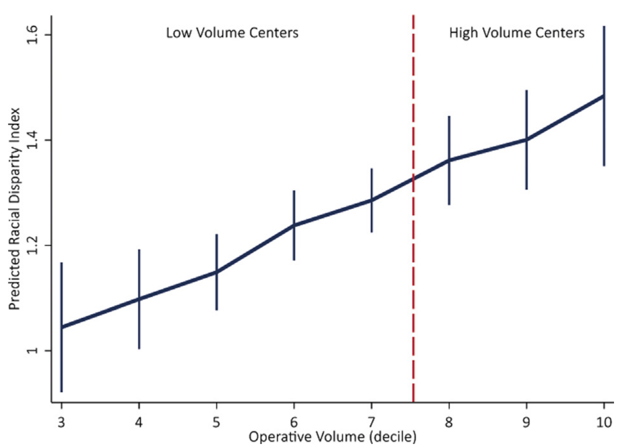

Figure 2. Predicted racial disparity index by operative volume (*RDI*, Racial Disparity Index; note: lowest 2 deciles dropped due to Healthcare Cost and Utilization Project guidelines, Midline: separating high and low-volume centers).

Volume-Outcome relationship

Using a contemporary cohort, our study demonstrates a strong association between postoperative mortality and operative volume for various palliation stages of HLHS. The inverse relationship between operative volume and mortality has previously been established in both adult and pediatric surgical populations.[13,31,32] This association has been ascribed to several factors, including individual surgeon and team experience, while others have pointed to improved perioperative management at high-volume centers.[33] Our study adds a contemporary examination of this effect in a specialized surgical cohort. Interestingly, despite reduced mortality at high-volume centers, there was no difference noted in rates of complications. This finding is supported by studies suggesting that higher-volume centers are better at "rescue," ie, identifying and managing complications in the perioperative setting.[34] The role of program consolidation to high-performing centers remains controversial as stakeholders weigh optimization of outcomes against access to a smaller number of centers.

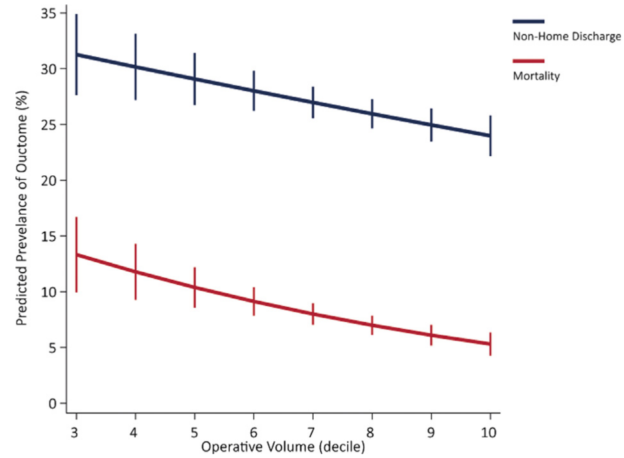

Figure 3. Predicted prevalence of non-home discharge and mortality by operative volume (note: lowest 2 deciles dropped due to Healthcare Cost and Utilization Project guidelines).

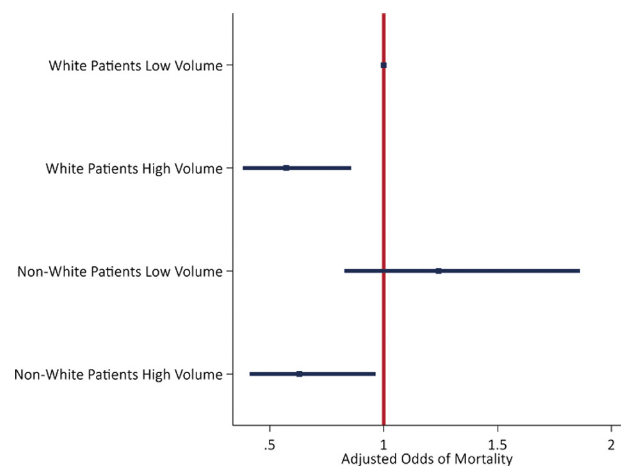

Figure 4. Adjusted odds of mortality by race and operative volume.

Racial disparities by operative volume

In the present work, higher-volume centers were more likely to serve White patients as evidenced by the RDI. Using a novel normalizing methodology, we calculated a racial inequality score that accounted for variations in the demographic composition of each hospital and identified significant disparities in access to high-performing, high-volume centers. High-volume centers treat dramatically higher proportions of White patients than would be expected based on local demographics. We have further demonstrated a profound, incremental increase in RDI with increasing operative volume for HLHS. The phenomenon of access disparities has been described in prior research demonstrating lower treatment rates for minority adults at high-volume cancer, orthopedic, and cardiovascular care centers.[35] Further, in our study, we found that patients at high-volume centers were more often privately insured, and median household income was greater. Others have supported our findings, identifying greater variation in clinical

Table III
Impact per volume decile on adjusted clinical outcomes using multivariable regression models

Outcome	Impact per volume decile increase	95% confidence interval	P value	C-statistic
Mortality (AOR)	0.86	[0.81–0.91]	<.001	0.79
Any complication (AOR)	0.95	[0.90–1.00]	.06	0.75
Non-home discharge (AOR)	0.95	[0.91–0.99]	.02	0.76
Cost (β, $)	+1,708	[-2,187 to 5,604]	.55	-
Postoperative length of stay (β, days)	- 0.23	[-0.81 to 0.35]	.19	-

AOR, adjusted odds ratio; *β*, beta coefficient; *C-statistic*, area under the receiver operating characteristic curve, model variables selected using elastic net methodology.

outcomes between hospitals volumes rather than differential treatment within centers.[36–38] Establishment of referral guidelines and provision of support services to families of children with HLHS may serve to provide improved care to this vulnerable cohort irrespective of race.

Access to expert facilities by race

Both White and non-White patients benefited from the improved care at high-volume centers, with no clear mortality differences between the 2 groups once adjusted for annual operative volume. This finding indicates that mortality differences by race exist due to disparate access to HVC, rather than differential treatment of non-White patients within a specific center. Differential access to high-volume centers and their improved outcomes has been borne out in prior research. Chan et al first reported that Black children are more likely to receive treatment at hospitals with higher mortality for congenital cardiac surgery.[9] Huang and associates also demonstrated that racial minorities were less likely to use high-volume hospitals despite geographic proximity, a phenomenon that they ascribed to lower levels of patient education and weaker referral patterns.[39,40] In the case of congenital cardiac surgery, access to prenatal screening may further explain the discrepancies in HVC access. Given the complexities of first-stage palliation for HLHS, one might expect the Norwood procedure to be preferentially performed at high-volume centers.[41] However, we found a similar distribution of operative stage as well as age among high and low-volume centers, suggesting the absence of referrals to expert facilities based on antenatal diagnosis. While the role of prenatal diagnosis in improving HLHS outcomes remains controversial, efforts to increase antenatal diagnosis of HLHS may subsequently guide referral to high-performing centers.[42] Further work to ameliorate racial disparities in prenatal care and detection may improve HLHS detection and increase referrals to high-volume hospitals.

Future directions

The present study offers a contemporary analysis of racial disparities in access to high-quality care. While the factors driving this access variation are beyond the scope of the study, it is important to consider the impact of policy on these disparities. The Leapfrog guidelines were implemented in 2012 to establish minimum volume standards for high-risk procedures.[43] Yet these guidelines considered surgical volume as an end goal to improve patient outcomes rather than access to care. While volume standards have been shown to improve perioperative outcomes, the current study indicates that not all groups are reaping the benefits of these polices.[44] Future iterations of volume cut-offs must consider access disparities as a central factor to measure success of such programs. Further, standardized referral guidelines for both pregnant individuals and children with HLHS may be implemented to improve access and, therefore, outcomes overall for children suffering from HLHS.

Limitations

There are several important limitations to our study inherent to its retrospective design and the nature of NIS data. As with any administrative database, the NIS is susceptible to inaccuracies in coding. Clinical characteristics such as echocardiogram findings and patient-specific anatomical and functional traits that affect perioperative complexity cannot be captured sufficiently in administrative-based coding. Furthermore, we were unable to comment on the effect of individual surgeon volume, which has been previously shown to impact outcomes.[45] Importantly, we do not know the true demographic composition for each hospital's catchment area. Respiratory failure functions as a reasonable surrogate for local care, but HLHS patients may travel tremendous distances to reach appropriately equipped treatment facilities. Such travel may be economically beyond the means of many families. Despite these limitations, we used novel normalizing methodology to examine nationally representative outcomes for a large cohort of patients with HLHS and describe the unique role that access to high-volume centers may play in driving racial disparities.

In conclusion, this study represents a novel and comprehensive population-based examination of operative HLHS patients, which highlights stark racial and volume discrepancies in care. Operative management of HLHS requires a dedicated multidisciplinary team equipped to handle such significant surgical and perioperative complexity. We have demonstrated high-volume centers to disproportionally serve White patients. Moreover, the association of race and mortality disappeared within centers of similar operative volume, suggesting inter- rather than intrahospital disparities in care. Our findings highlight the critical importance of equitable access to high-performing centers for the spectrum of complex palliative operations in HLHS. Our findings have important implications in health care access and provide further impetus for measures directed at improving prenatal management, patient education, financial support and equitable referral for those with a diagnosis of HLHS.

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Conflicts of interest/Disclosure

The authors report no proprietary or commercial interest in any product mentioned or concept discussed in this article.

Supplementary materials

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