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Systemic Barriers in End-of-Life Care for Neuro-Emergencies: Temporal, Racial, and Disease-Specific Disparities Among ICH/SAH Decedents, 1999–2020

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Abstract

Background

Timely transition to hospice care is critical for reducing avoidable suffering in neuro-emergencies like intracerebral hemorrhage (ICH) and subarachnoid hemorrhage (SAH). However, registry-based research often overlooks structural discontinuities in outcome reporting and lacks rigorous examination of system-level barriers. This study aimed to unveil structural inequities—specifically the "weekend effect" and race-urbanicity interactions—concealed behind the overall growth in hospice utilization.

Methods

We conducted a retrospective population-based cohort study of US decedents using CDC WONDER data (1999–2020). Joinpoint regression was first employed to validate structural reporting breakpoints, establishing a comparable "mature period" (2005–2020) while excluding unstable early data. Mixed-effects negative binomial regression models with prespecified interaction terms and bootstrap resampling were applied to quantify the independent and interactive effects of timing, disease phenotype, and geo-racial factors.

Results

Among 344,211 decedents in the mature period, hospice utilization increased significantly but exhibited profound stratified disparities. First, utilization for SAH remained consistently half that of ICH. Second, a systemic "weekend effect" was identified, where weekend death was associated with a ~ 53–56% reduction in hospice utilization (aRR ~ 0.45) across both pathologies, highlighting administrative failure in off-hour referral pathways. Third, interaction models revealed a "double jeopardy" phenomenon: the benefits of urbanization were heavily racialized. While urban Non-Hispanic Whites had the highest utilization, urban Non-Hispanic Blacks had rates (0.37%) significantly lower than even rural Whites (0.53%).

Conclusions

The expansion of hospice for neuro-emergencies is not linearly homogeneous but shaped by early reporting instability and persistent system-level barriers. The institutional void during weekends and the racial capture of urban advantages constitute major impediments to equity. Physical resource density (urbanization) does not automatically translate into equitable health gains. Achieving true equity requires establishing 24/7 palliative assessment pathways and implementing targeted structural interventions to dismantle these rigidities.

1. Introduction

Non-traumatic intracerebral hemorrhage (ICH) and subarachnoid hemorrhage (SAH) are among the most lethal neurosurgical emergencies.(1–4) Their clinical courses often necessitate urgent decisions regarding life-sustaining therapies, symptom management, and goals of care within a critically narrow time window.(5) For patients suffering from catastrophic brain injury or facing a poor prognosis, a timely transition to comfort-oriented care models not only mitigates avoidable suffering but also provides critical support to families during arduous decision-making processes.(6, 7) Consequently, hospice care, as an established model of end-of-life care, is highly relevant to neurocritical clinical pathways.(8)

Despite urgent clinical needs, hospice utilization among decedents with neuro-emergencies remains limited and unevenly distributed across populations.(9–12) While prior studies have documented racial/ethnic and geographic disparities,(13–15) most registry-based literature implicitly assumes that time is homogeneous and comparable across long observation windows. However, for "institution-sensitive outcomes" recorded on death certificates—such as "hospice facility" as the place of death—this assumption may not hold. Changes in coding availability, shifts in documentation practices, and the evolution of system integration can introduce "structural discontinuities," thereby altering the observability and stability of the outcome itself.(16–18) Ignoring these breakpoints may bias estimates or, in extreme cases, result in numerical instability.

Furthermore, end-of-life transitions in ICH and SAH are uniquely time-sensitive.(19) Unlike chronic diseases, the clinical trajectories of neuro-emergencies typically evolve over hours to days, concentrating discussions on goals of care and referral processes within the first 24–72 hours of hospitalization. (20) This time-critical transition relies on the tight collaboration of interdisciplinary teams (e.g., attending physicians, social work/case management, palliative care services), a capacity that may differ significantly between weekdays and weekends.(21) Thus, the "weekend effect" may represent a system-level barrier to hospice transition rather than a preference difference at the individual level,(22) yet disease-specific evidence for neuro-emergencies is currently lacking.

Finally, urbanicity is often treated as a proxy for access to healthcare resources, but physical resource density does not guarantee equitable access.(22–24) While urban environments increase the overall supply of hospice services, they may also mask differential benefits among racial/ethnic groups—specifically, if culturally and linguistically appropriate communication, patient-provider trust, and referral pathways are not implemented evenly, the "urban advantage" may be structurally intercepted.(25, 26)

Based on this, using U.S. national mortality data from 1999–2020, this study aims to examine hospice utilization patterns among ICH and SAH decedents. We pursued three core objectives: (1) to validate structural discontinuities in hospice reporting over time and implement a stage-based analytic framework; (2) to quantify the impact of disease-specific weekend effects on hospice utilization; and (3) to evaluate race/ethnicity-by-urbanicity interactive inequities. By explicitly addressing temporal non-comparability and employing prespecified interaction models with robustness checks, this study seeks

to provide public-health-relevant empirical evidence for understanding system-level barriers and equity gaps in end-of-life care for neuro-emergencies.

2. Methods

Study Design and Population

We conducted a retrospective population-based cohort study using the CDC WONDER Multiple Cause of Death database (1999–2020). (27) The cohort included all decedents with an underlying cause of death coded as non-traumatic intracerebral hemorrhage (ICH; ICD-10 I61) or subarachnoid hemorrhage (SAH; I60). To capture the population with a clinical window for potential hospice referral, we excluded deaths recorded as "Dead on Arrival" or occurring in emergency departments.Institutional Review Board approval and informed consent were not required because the data are de-identified and publicly available. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.

Variables

The primary outcome was hospice utilization, operationalized as the place of death recorded as "hospice facility." Key exposures included weekend timing (Saturday/Sunday vs. weekdays) and disease type (ICH vs. SAH). Covariates included age group (< 65 vs. ≥65 years), sex, race/ethnicity (Non-Hispanic [NH]-White, NH-Black, NH-Asian/Pacific Islander, Hispanic), urbanicity (NCHS classification), and U.S. Census Region.

Temporal Segmentation

To address potential structural non-comparability in hospice reporting over time, we performed Joinpoint regression to identify trend breakpoints (Supplementary material 1,eFigure 1). Based on these breakpoints, the study timeline was stratified into three phases: Implementation (P1: 1999–2004), Growth (P2: 2005–2015), and Mature (P3: 2016–2020). Primary inference models were restricted to the stable P2–P3 periods (2005–2020) to ensure reliability.

Statistical Analysis

We fitted multivariable mixed-effects negative binomial regression models with state-level random intercepts to account for geographic clustering. Prespecified interaction terms included Weekend × Disease (to assess phenotype-specific barriers) and Race × Urbanicity (to evaluate equity in urban resource distribution). Results are reported as adjusted Rate Ratios (aRRs) with 95% Confidence Intervals (CIs). Robustness was assessed via 1,000 nonparametric bootstrap resamples to address potential overdispersion (Supplementary material 1,eFigure 2). As a sensitivity analysis, we included the P1 period to evaluate the stability of estimates under temporal heterogeneity (Supplementary material 2,eTable 3).

3. Results

3.1 Baseline Characteristics of the Study Cohort

The final analytic cohort for the mature period (2005–2020) comprised 344,211 decedents (Table 1). Spontaneous intracerebral hemorrhage (ICH) accounted for the majority of deaths (n = 262,100; 76.1%), while subarachnoid hemorrhage (SAH) comprised 23.9% (n = 82,111).

Demographic characteristics differed significantly by pathology, most notably in age structure. The SAH cohort was markedly younger, with 51.2% of decedents aged < 65 years compared to only 25.8% in the ICH cohort. The racial and ethnic distribution was predominantly Non-Hispanic White (73.9%), followed by Non-Hispanic Black (13.3%) and Hispanic (8.4%). Notably, the proportion of Hispanic decedents was slightly higher in the SAH group (11.2%) than in the ICH group (7.6%).

Geographically, the South (Census Region 3) bore the highest mortality burden, accounting for 39.5% of all deaths, a finding consistent with established "Stroke Belt" epidemiology. The vast majority of deaths occurred in urban or metropolitan areas (81.8%). Regarding temporal exposure, 27.3% of deaths occurred on weekends, with a similar distribution observed across the ICH (27.6%) and SAH (26.5%) subgroups.

Table 1
Demographic Characteristics of the Study Population, 2005–2020[a].

	Total Cohort (N = 344211)	SAH (N = 82111)	ICH (N = 262100)
Timing of Death (Exposure)			
Weekday	250211 (72.7%)	60340 (73.5%)	189871 (72.4%)
Weekend	94000 (27.3%)	21771 (26.5%)	72229 (27.6%)
Age Group			
< 65 years	109654 (31.9%)	42032 (51.2%)	67622 (25.8%)
≥ 65 years	234557 (68.1%)	40079 (48.8%)	194478 (74.2%)
Race/Ethnicity			
Non-Hispanic White	254403 (73.9%)	58361 (71.1%)	196042 (74.8%)
Non-Hispanic Black	45847 (13.3%)	10471 (12.8%)	35376 (13.5%)
Hispanic	29035 (8.4%)	9166 (11.2%)	19869 (7.6%)
Asian/Pacific Islander	14926 (4.3%)	4113 (5.0%)	10813 (4.1%)
Urbanization			
Rural (Non-Metro)	62636 (18.2%)	13445 (16.4%)	49191 (18.8%)
Urban (Metro)	281575 (81.8%)	68666 (83.6%)	212909 (81.2%)
Census Region			
Census Region 1: Northeast	59541 (17.3%)	14487 (17.6%)	45054 (17.2%)
Census Region 2: Midwest	79116 (23.0%)	18056 (22.0%)	61060 (23.3%)
Census Region 3: South	135931 (39.5%)	31689 (38.6%)	104242 (39.8%)
Census Region 4: West	69623 (20.2%)	17879 (21.8%)	51744 (19.7%)

a. Data source: CDC WONDER. Analysis restricted to 2005–2020 (Phase 2 & 3) to ensure coding consistency.

3.2 Temporal Trends and Validated Structural Breakpoints

Joinpoint regression analysis confirmed significant temporal phasing in hospice reporting, supporting a stage-based analytic approach. Quantitative analysis identified two key structural breakpoints at years 2004.5 and 2015.5 (Supplementary material 2,eTable 1 and Supplementary material 1,eFigure 1). The initial phase (P1: 1999–2004) exhibited statistical volatility characteristic of early system

implementation (slope 0.006, $P < 0.001$) combined with extremely low outcome capture rates; consequently, it was characterized as a "washout period" and excluded from inference models (Fig. 1).

The subsequent phase (P2: 2005–2015) represented a relatively stable plateau (slope − 0.0003, $P = 0.911$), while the contemporary period (P3: 2016–2020) marked a resurgence of significant positive growth in hospice utilization (slope 0.009, $P < 0.001$). Although both pathologies showed upward trends during the mature period, the magnitude of growth differed significantly. The crude utilization rate for intracerebral hemorrhage (ICH) more than doubled from 4.73% in P2 to 10.19% in P3. In contrast, while subarachnoid hemorrhage (SAH) utilization also increased from 2.59% to 5.56%, it remained consistently lower throughout the study period, hovering at approximately half the rate of ICH. This persistent gap highlights a marked divergence in end-of-life care pathways based on disease phenotype.

3.3 Multivariable Analysis of Hospice Utilization

In the primary multivariable model for the mature period (Supplementary material 2,eTable 2), temporal and geographic factors emerged as robust predictors. Hospice utilization was more than two-fold higher in the contemporary period (P3) compared to the reference period (aRR 2.13, 95% CI 1.99–2.28) and nearly 82% higher in urban settings compared to rural areas (aRR 1.82, 95% CI 1.64–2.02).

Demographic disparities were pronounced; notably, younger age (< 65 years) was associated with a substantially lower likelihood of hospice transition (aRR 0.26, 95% CI 0.23–0.29). Racial and ethnic estimates also varied significantly relative to the reference group.

Of particular interest regarding the "weekend effect," the averaged main effect in this global model was near the null and marginally non-significant (aRR 0.93, 95% CI 0.86–1.00; $P = 0.053$). This finding motivated our prespecified evaluation of disease-specific weekend effects via interaction modeling to determine if this aggregated null result masked heterogeneous patterns between ICH and SAH.

3.4 Disease-specific Weekend Effects (Aim 2)

To investigate the marginally significant weekend effect observed in the aggregate model ($P = 0.053$), we employed a Bootstrap resampling model (n = 1,000) with interaction terms to interrogate disease-specific impacts. The analysis revealed a substantial and significant negative impact of weekend timing on hospice utilization, an effect that was highly consistent across both pathological subtypes (Fig. 2).

Specifically, for decedents with subarachnoid hemorrhage (SAH), the adjusted Rate Ratio (aRR) for hospice transition decreased to 0.44 (Bootstrap 95% CI 0.30–0.61) on weekends compared to weekdays. Similarly, decedents with intracerebral hemorrhage (ICH) experienced a marked reduction in hospice access on weekends, with an aRR of 0.47 (Bootstrap 95% CI 0.34–0.61).

Diagnostic evaluation of the Bootstrap distributions (Supplementary material 1,eFigure 2) revealed highly overlapping and unimodal density plots for both effect estimates. This suggests that the observed weekend effect is not driven by outliers but rather reflects systemic barriers to weekend care—such as staffing shortages in referral coordination or admission restrictions at receiving facilities. These

structural barriers appear to affect neuro-emergency patients uniformly, regardless of their specific hemorrhagic subtype.

3.5 Structural Barriers: Race-by-Urbanicity Interactions (Aim 3)

Analysis of predicted probabilities revealed that the "urban advantage" in hospice utilization was unevenly distributed across racial groups, heavily skewed toward the majority population (Fig. 3). Non-Hispanic White decedents exhibited the steepest geographic gradient, with predicted hospice utilization nearly quadrupling from 0.53% in rural areas to 1.97% in urban centers. In stark contrast, minority groups faced persistent structural barriers that blunted the potential benefits of urbanization.

Notably, Non-Hispanic Black decedents residing in resource-rich urban areas had a predicted utilization rate of only 0.37%—a level significantly lower than that of White decedents residing in resource-poor rural areas (0.53%). This inversion suggests that the impact of racial disparities supersedes the geographic accessibility of healthcare resources. Furthermore, for Asian and Hispanic populations in rural settings, hospice utilization was virtually nonexistent (< 0.001%), indicating a near-total absence of specialized end-of-life infrastructure at the intersection of racial and geographic marginalization.

3.6 Sensitivity Analysis: Inclusion of the Early Period (1999–2004)

To evaluate the impact of model specification on our findings, we constructed a sensitivity model that included the early phase (P1: 1999–2004) (Supplementary material 2,eTable 3). The analysis revealed that including P1 introduced extreme numerical instability in time-related parameter estimates. Specifically, the effect estimate for the contemporary period (P3) inflated dramatically from 2.13 in the main model to 1.37×10^{9} in the sensitivity model1. This phenomenon is attributable to the extremely low baseline capture rate of hospice utilization—an "institution-sensitive outcome"—during the early phase, confirming the structural non-comparability of data from this period.

Crucially, however, effect estimates for key demographic, clinical, and geographic covariates exhibited remarkable stability. Regardless of the inclusion of early data, the adjusted Rate Ratios (aRRs) for age, race/ethnicity, urbanicity, and weekend effects remained constant. For instance, the weekend effect was identical in both the sensitivity and main models (aRR 0.926), as was the effect for Non-Hispanic Black decedents (aRR 1.288). These findings strongly support the robustness of the primary analysis, indicating that the structural disparities revealed in this study are genuine phenomena rather than statistical artifacts resulting from the selection of a specific temporal window.

4. Discussion

Through a systematic analysis of 20 years of national data on ICH and SAH decedents, this study reveals significant structural discontinuities in hospice utilization over time, alongside persistent system-level

barriers during the mature reporting phase. While hospice utilization appears to follow an upward trend on the surface, this growth masks three intersecting fractures: measurement instability in the temporal dimension, an institutional void during weekends, and the structural interception of urban advantages by racial inequities. Together, these findings suggest that treating "institution-sensitive outcomes" as temporally homogeneous variables without accounting for the evolution of their observability and institutional context may introduce systematic bias.

4.1 Structural Discontinuity and Methodological Implications for Registry Research

Our Joinpoint analysis confirmed that hospice reporting was not stable throughout the study period but rather exhibited distinct phases, most notably a volatile early period (1999–2004) characterized by extremely low utilization. Crucially, sensitivity analyses demonstrated that forcing this early phase into the model resulted in order-of-magnitude instability in time-related effect estimates, whereas estimates for other sociodemographic and clinical covariates remained remarkably consistent. This “selective instability” suggests that the anomalies observed in the early phase are unlikely to be explained by random noise alone and are consistent with structural non-comparability of the outcome itself, potentially stemming from the incomplete institutionalization of hospice coding in vital statistics, inconsistent place-of-death reporting rules, and variation in documentation practices across facilities. These findings align with prior research indicating that long-term surveillance using administrative and death certificate data is susceptible to biases from evolving coding practices.(28)

Methodologically, our results underscore that researchers using long-horizon registry or vital statistics data for public health surveillance and equity research should not default to assuming linear comparability of temporal trends. Instead, explicit testing for potential temporal breakpoints is essential. Neglecting this step risks obscuring genuine institutional shifts or generating directionally misleading inferences about trends.

4.2 The Weekend Effect: A System-Level Barrier to Time-Sensitive Transitions

In disease-specific interaction models, we observed that weekend death was associated with a significant reduction—approximately 53%–56%—in hospice utilization for both SAH and ICH decedents. This finding argues against attributing the observed disparities solely to individual or family preferences, and instead suggests the presence of structural capacity constraints within the healthcare system during weekends. Neuro-emergencies are characterized by a highly compressed clinical timeline, where goals-of-care discussions and hospice referrals often concentrate within the first 24–72 hours of hospitalization. In this context, the reduced availability of social work and case management services, fewer formal family meetings, and delayed specialist support on weekends may exert an amplified negative impact on referral processes.(29) This mechanism is consistent with the widely reported

"weekend effect" in stroke and other acute conditions, where weekend timing remains associated with poorer process-of-care metrics and outcomes even after adjustment for disease severity.

Notably, the main effect of weekend timing in the aggregate model was near-null, contrasting sharply with the strong disease-specific effects revealed in interaction models. This discrepancy suggests that systemic barriers may only become visible in clinical contexts that are highly time-sensitive and dependent on rapid institutional response. Consequently, this study supports the integration of standardized, 24/7 palliative assessment triggers and referral coordination services into neurocritical and stroke care pathways to reduce structural reliance on weekday-only resource configurations.

4.3 Unequal Distribution of the Urban Advantage and Challenges to Health Equity

Although urbanicity was generally associated with higher hospice utilization, the benefits of this "urban advantage" were distributed highly unevenly across racial/ethnic groups.(23) Non-Hispanic White decedents benefited most from urban resource density; in contrast, predicted utilization for Non-Hispanic Asian/Pacific Islander decedents remained extremely low even in highly urbanized areas. Even more strikingly, hospice utilization rates for urban Black populations were lower than those for rural White populations.

This pattern indicates that physical resource density alone does not automatically translate into equitable health gains. Prior research has repeatedly highlighted structural inequities within urban healthcare systems, including deficits in culturally and linguistically appropriate communication, historical breaches of patient-provider trust, and the cumulative effects of implicit bias in referral pathways.(30, 31) In this context, urbanization may exacerbate benefit gaps between groups while increasing overall supply, effectively causing the "urban dividend" to be structurally intercepted.

From the perspective of implementation science for equity, these results suggest that interventions focused solely on expanding facility capacity or bed supply may be insufficient to substantially improve end-of-life care accessibility for marginalized groups. Instead, more promising strategies include establishing culturally responsive communication infrastructure, systematically integrating professional interpreter and navigation services, and implementing standardized protocols to reduce reliance on subjective judgment and ad hoc resources in referral decisions.

4.4 Strengths and Limitations

This study has several notable strengths. We leveraged two decades of nationwide mortality data, enabling the examination of rare but clinically consequential neurologic emergencies with sufficient statistical power. By explicitly testing for temporal discontinuities and restricting inference to comparable reporting periods, we addressed a common but underappreciated challenge in registry-based and vital statistics research. In addition, the use of prespecified interaction models allowed us to identify disease-specific and context-dependent system-level barriers that would not have been apparent in aggregate analyses.

Several limitations should also be acknowledged. First, hospice utilization was inferred from death certificate–based place-of-death reporting, which may be subject to misclassification and temporal changes in documentation practices. Although we explicitly addressed temporal non-comparability, residual measurement error cannot be fully excluded. Second, these data do not permit differentiation between hospice referral, enrollment, and duration of hospice care, nor do they capture patient or family preferences regarding goals of care. Third, while we observed pronounced racial/ethnic and urban–rural disparities, the underlying mechanisms—such as communication quality, trust, or implicit bias—cannot be directly measured using vital statistics data and should therefore be interpreted as hypothesized pathways rather than observed processes. Finally, as an observational study, our findings describe associations and system-level patterns rather than causal effects.

5. Conclusion

Using national long-horizon registry data, this study confirms that the expansion of hospice care for neuro-emergencies has not been a simple linear progression but is dually shaped by structural instability in early reporting and system-level barriers in the mature period. Our analysis underscores that long-term research on "institution-sensitive outcomes" should not presuppose temporal homogeneity; explicitly validating and excluding structurally unstable periods is a prerequisite for reliable inference.Within this rigorously validated mature reporting period, although hospice has become a mainstream option, its accessibility remains constrained by severe institutional rigidities. The pronounced weekend effect exposes a "time-sensitive referral barrier" within the acute care system during off-hours, while the race-by-urbanicity interaction demonstrates that mere physical resource density (urbanization) has not translated into equitable benefits. The "double jeopardy" faced by urban Black patients—structural exclusion amidst resource abundance—serves as a potent rebuttal to the assumption that geographic accessibility equates to equity.herefore, improving equity in neurocritical care cannot rely solely on the passive expansion of medical resources. Future system redesign must directly confront these structural impasses: this requires not only establishing "24/7" palliative assessment and referral pathways within neuro-emergency protocols but also implementing culturally and linguistically concordant communication mechanisms. Such reforms are essential to ensure that every end of life—regardless of when or where it occurs—is afforded equal dignity and care.

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki. The Ethics Committee of The Second People's Hospital of Lianyungang & The Oncology Hospital of Lianyungang waived the requirement for ethical approval and informed consent, as the study utilized publicly available, de-identified aggregate data from the Centers for Disease Control and Prevention (CDC) WONDER database.

Consent for publication

Not applicable.

Availability of data and materials

The raw mortality data analyzed during the current study are available in the CDC WONDER Multiple Cause of Death database repository, [https://wonder.cdc.gov/mcd.html]. The processed datasets generated and analyzed during the current study are included in this published article and its additional files.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Conceptualization: J.L. and D.C.; Methodology: J.L. and D.Z.; Software: J.L.; Validation: J.L. and D.Z.; Formal Analysis: J.L.; Investigation: J.L. and D.Z.; Resources: D.C.; Data Curation: J.L.; Writing – Original Draft: J.L.; Writing – Review & Editing: J.L., D.Z. and D.C.; Visualization: J.L.; Supervision: D.C.; Project Administration: D.C. All authors have read and agreed to the published version of the manuscript.

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Figures

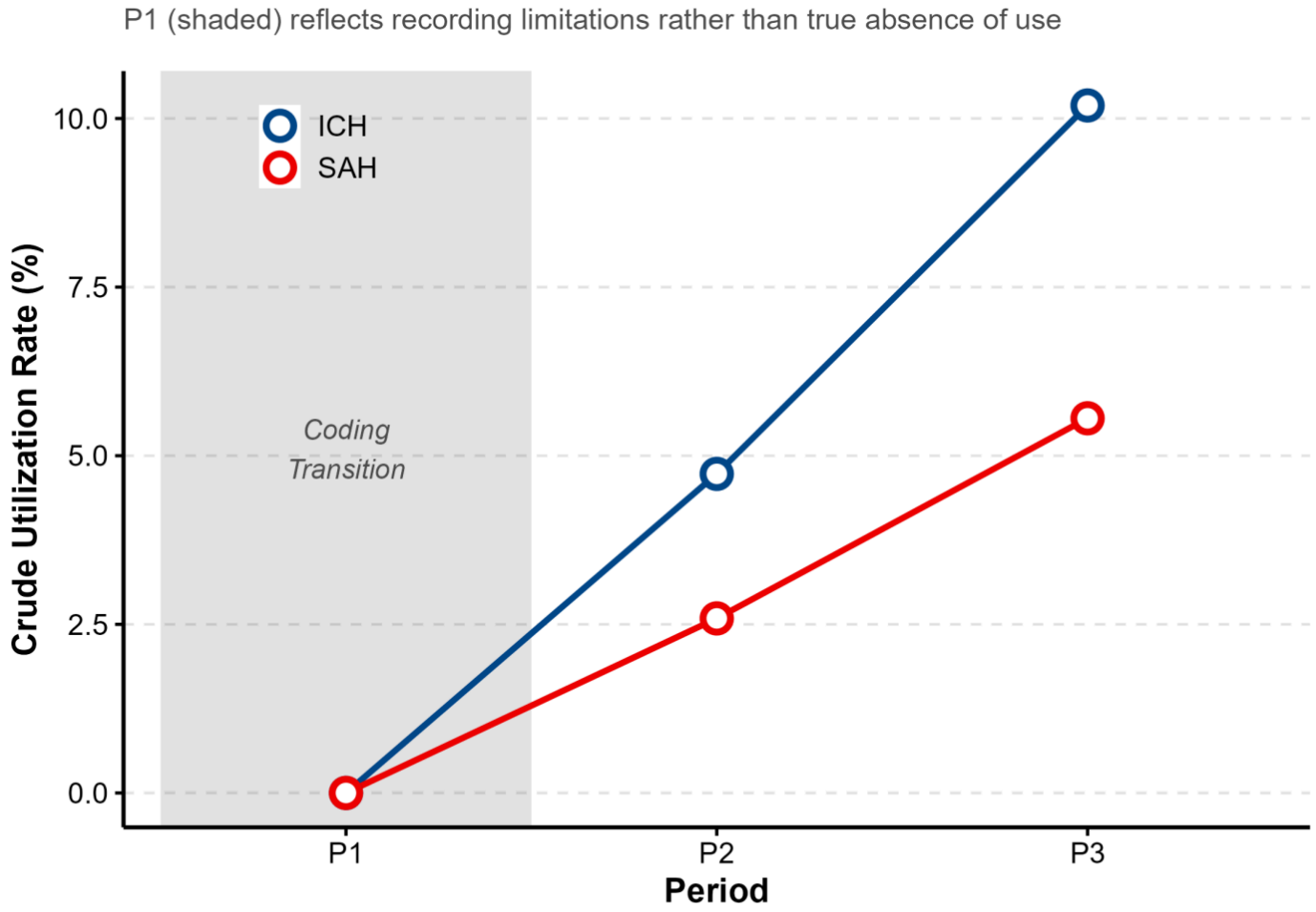


Figure 1

Temporal Trends (1999-2020).

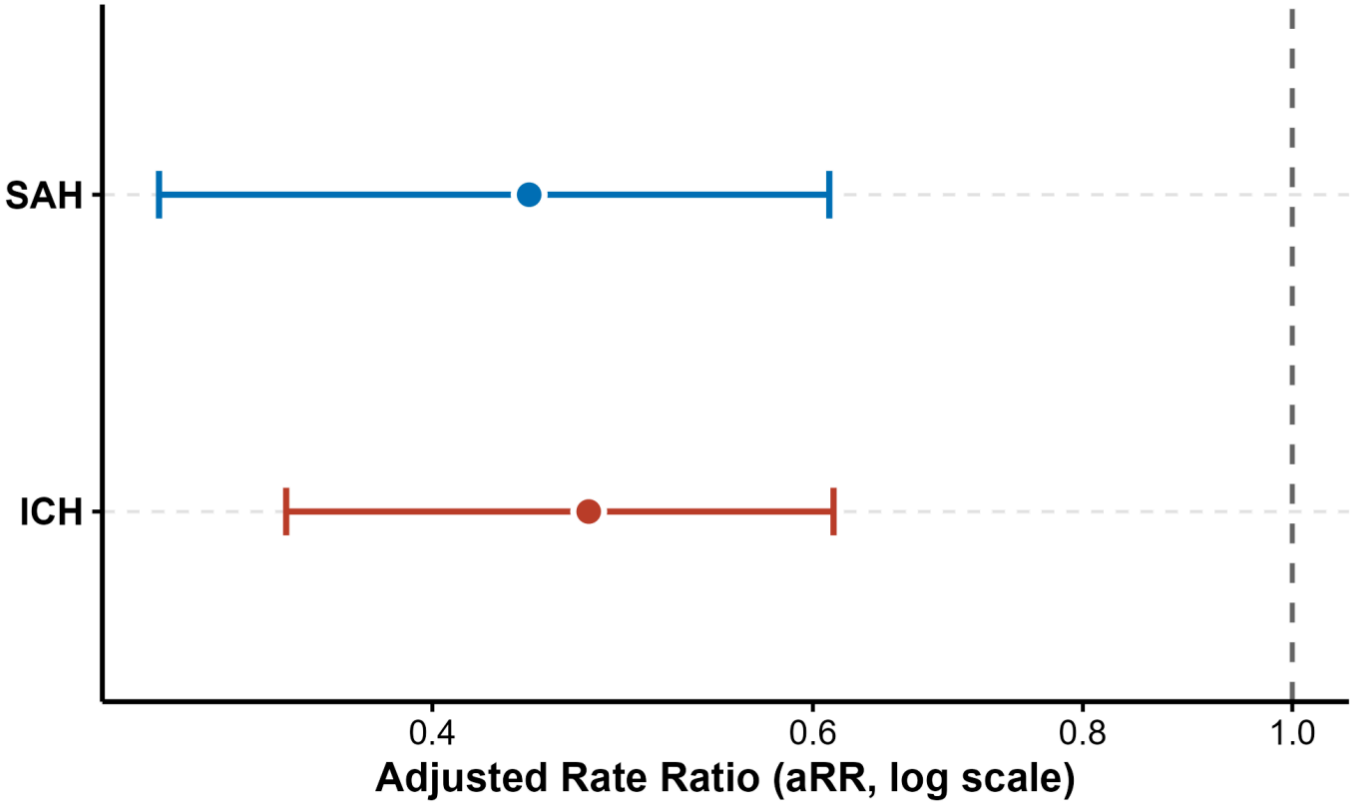


Figure 2

Weekend Effect (Bootstrap 95% CI,Phase 2 & 3 only).

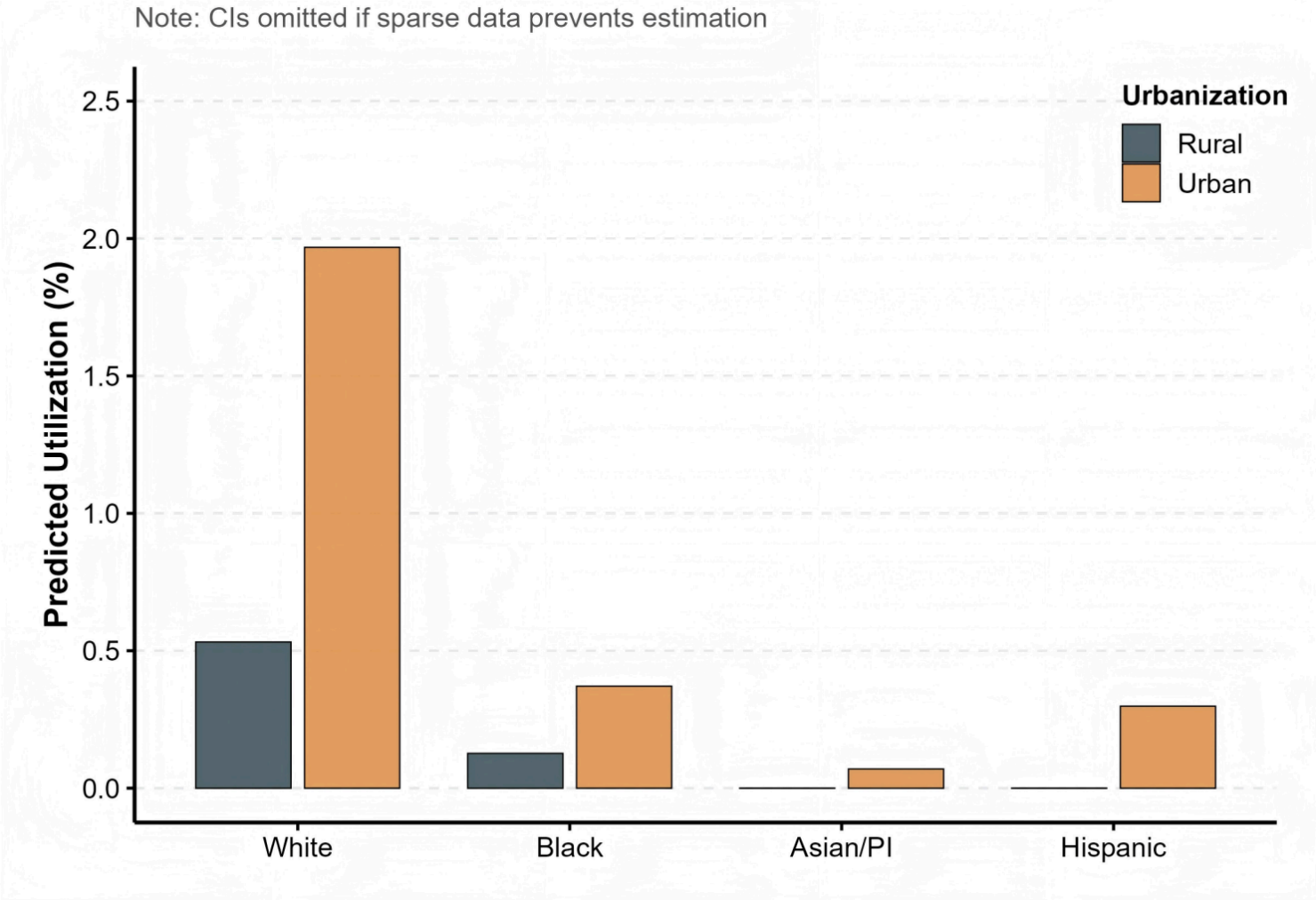


Figure 3

Structural Barriers: Racial & Geographic Disparities.

Supplementary Files

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- Supplementarymaterial1eFigure.doc
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