

Mortality and End of Life Care Issues among Rural Residents

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South Carolina Center for
Rural and Primary Healthcare

Overview

1. Rural mortality: current status
2. Current issues in mortality
3. End of life expenditures & utilization

Overview

1. Rural mortality: death rates and diagnostic contributors
2. Rural mortality: behavioral and resource contributors
3. End of life expenditures & utilization



Rural mortality: death rates and diagnostic contributors

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“At best, it would be illusory to consider national public health programs a success based on other indicators as long as inequalities in mortality and life expectancy fail to improve.” (Levine et al 2001 p. 480)



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Metrics for mortality

- Years of potential life lost: $75 - [\text{age at death}] =$ years of life lost
- Mortality rates: $\text{deaths}/\text{population} = \text{rate}$
 - ◆ Adjusted for age across communities
- Life expectancy (how long people live)
 - ◆ At birth
 - ◆ At mid-life



RWJ County Rankings data

- Index: years of potential life lost
 - ◆ Infant lives are important
 - ◆ Measures
- Time span: 1999 - 2013



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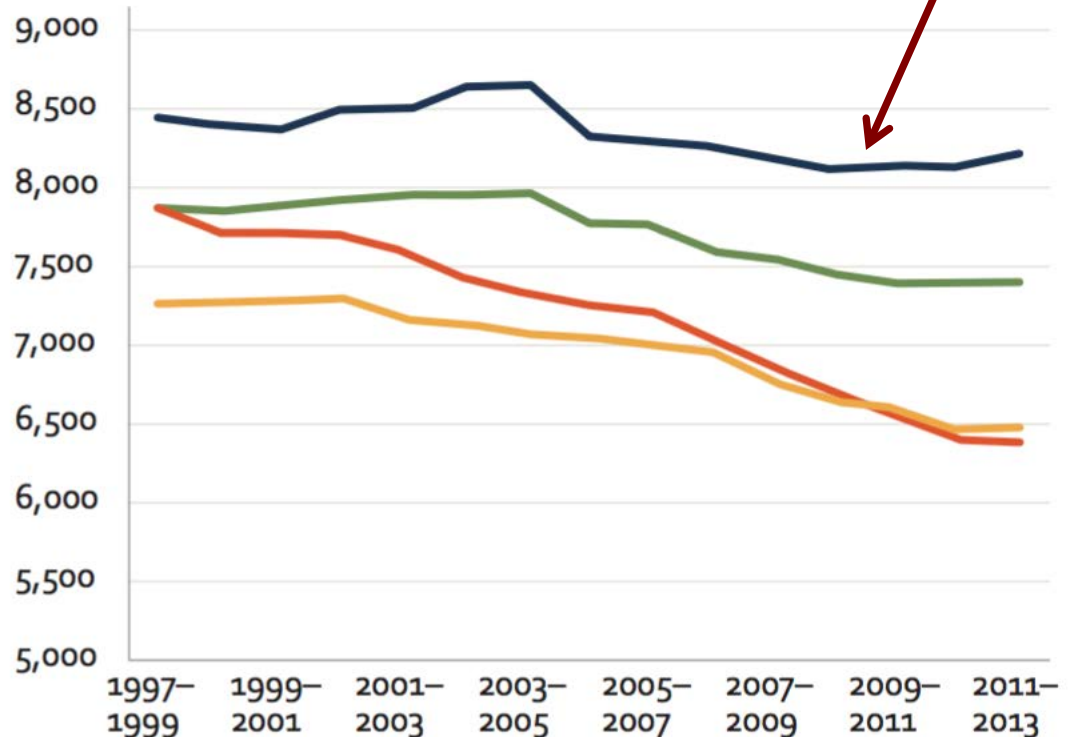


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Rural years of potential life lost: little decline

Category	Definition
Large Urban Metro	Central urban core counties within an MSA with more than 1 million people
Large Suburban Metro	Non-central fringe counties within an MSA with more than 1 million people
Smaller Metro	Counties within an MSA with between 50,000 and 1 million people
Rural	Non-metropolitan rural counties with less than 50,000 people

Premature Death Trends by Level of Urbanization
Years of potential life lost under age 75 per 100,000 people

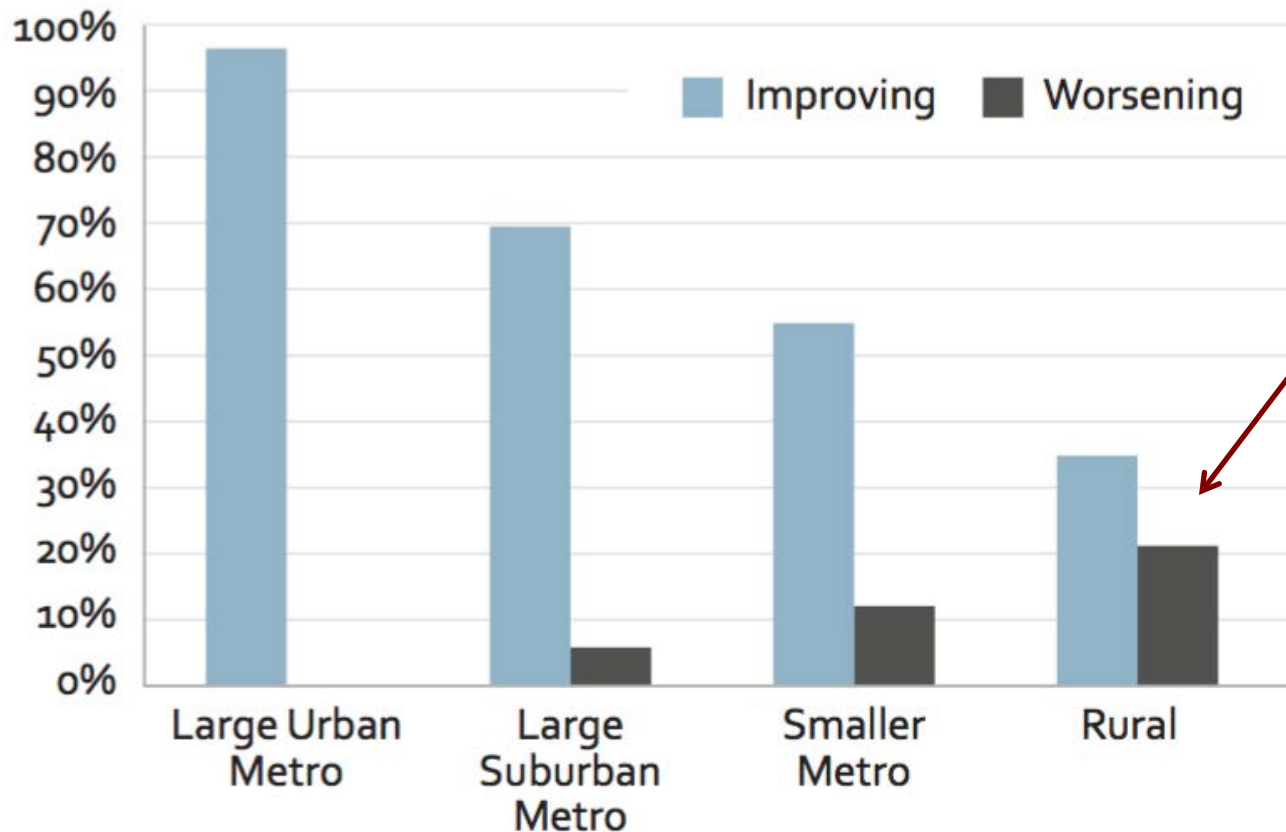


Source: University of Wisconsin Population Health Institute. *County Health Rankings Key Findings 2016*.

Years lost increased in 1 of every 5 rural counties

Counties with Improving or Worsening Premature Death Rates, 1999-2013¹

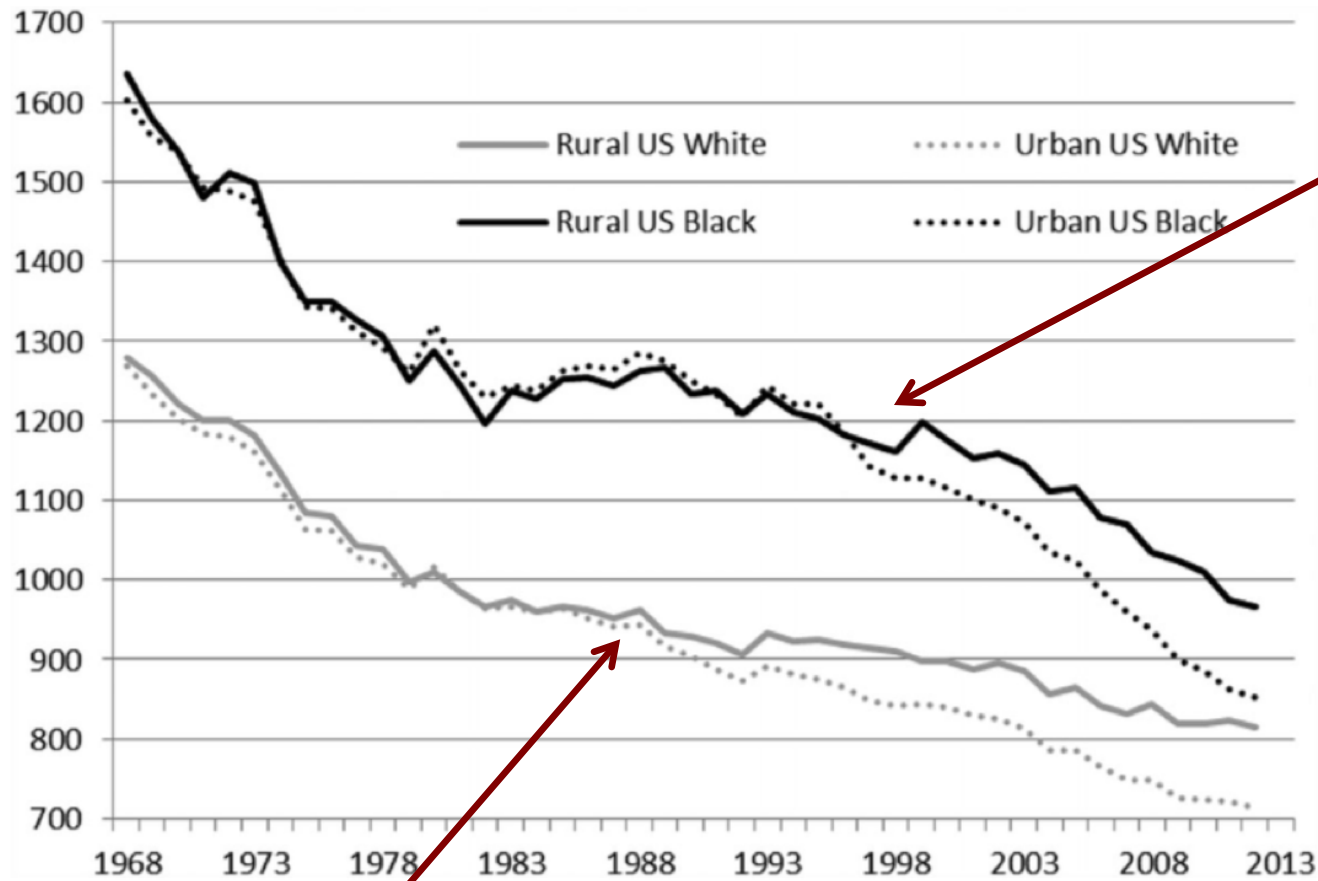
Percent of counties



Source: University of Wisconsin Population Health Institute. *County Health Rankings Key Findings 2016.*

Rural mortality disparities date to the 1980's

Age-adjusted mortality, by race and residence, 1968-2012



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Source: James & Cossman



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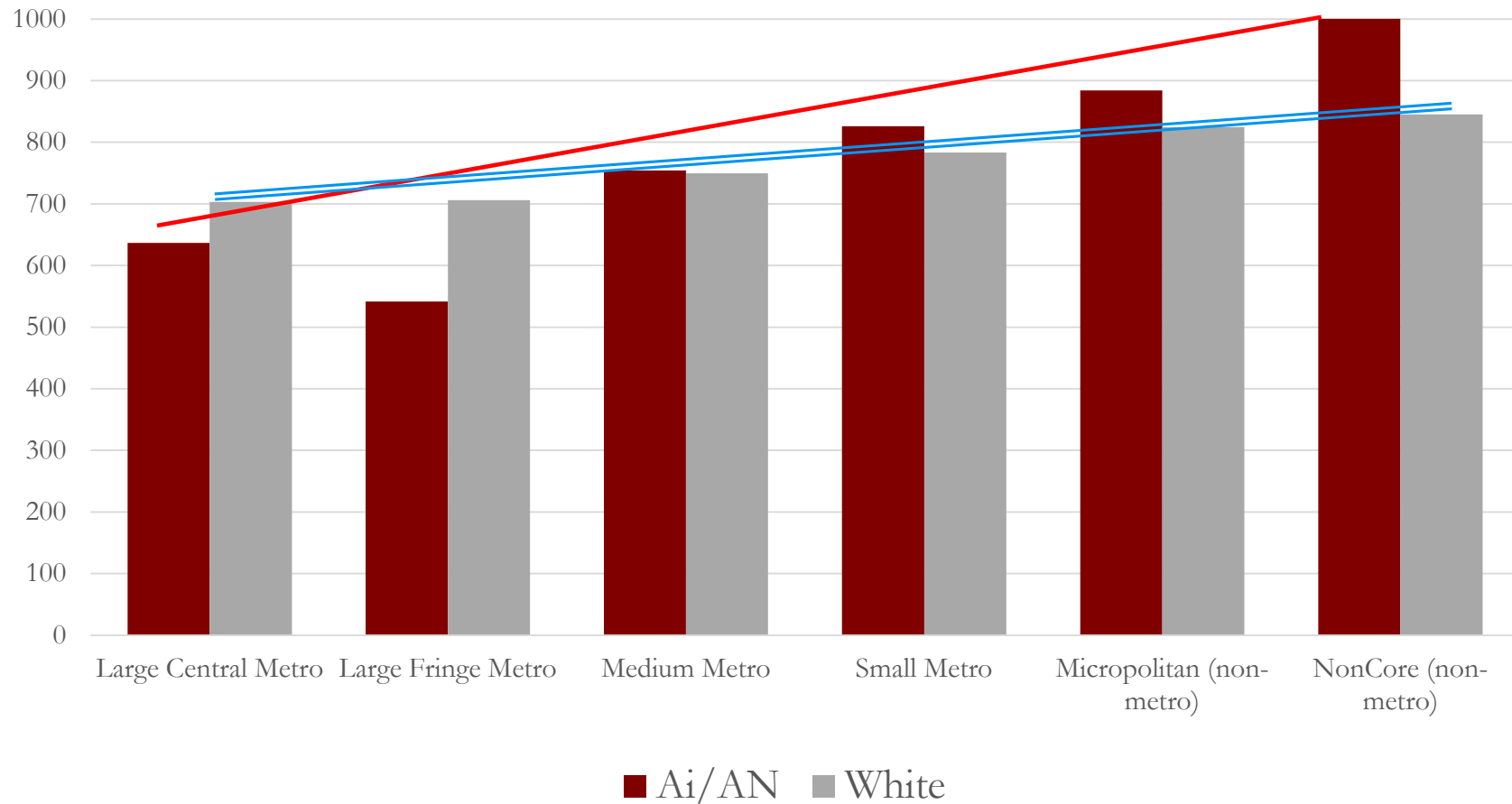
Death rates rise with rurality for some groups

- For American Indian/Alaska Native, African American, and White populations, death rates increase with rurality
- For Asian/Pacific Islander and Hispanic populations, the patterns are not clear





Death rates, AI/AN and White



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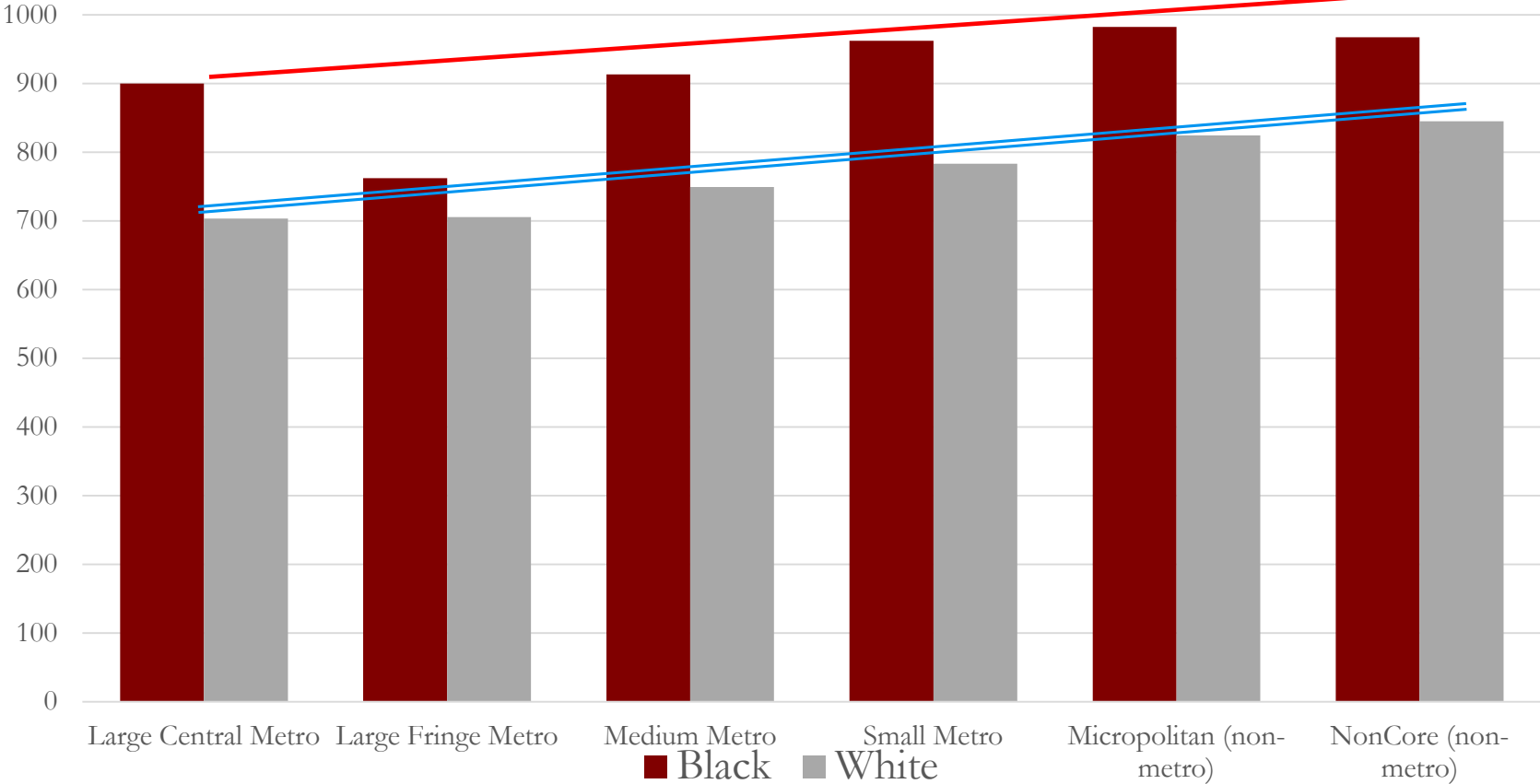
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Author's analysis; CDC 2016 WONDER data, both sexes



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Death rates, African American and White



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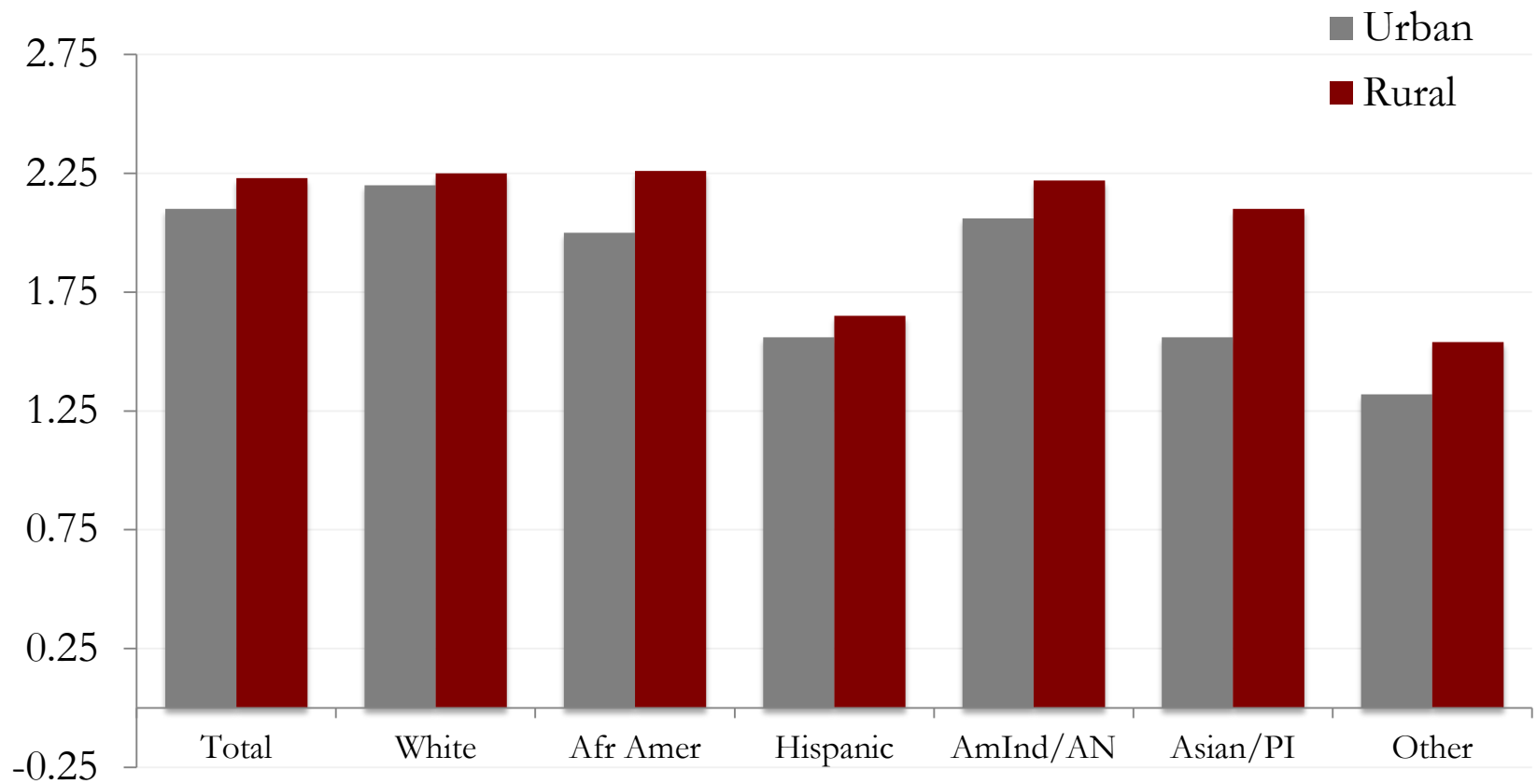
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Author's analysis; CDC 2016 WONDER data, both sexes



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Among dual eligible beneficiaries...



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- Which disorders/diseases contribute to higher rural death rates for white, black and American Indian/Alaska Native populations?



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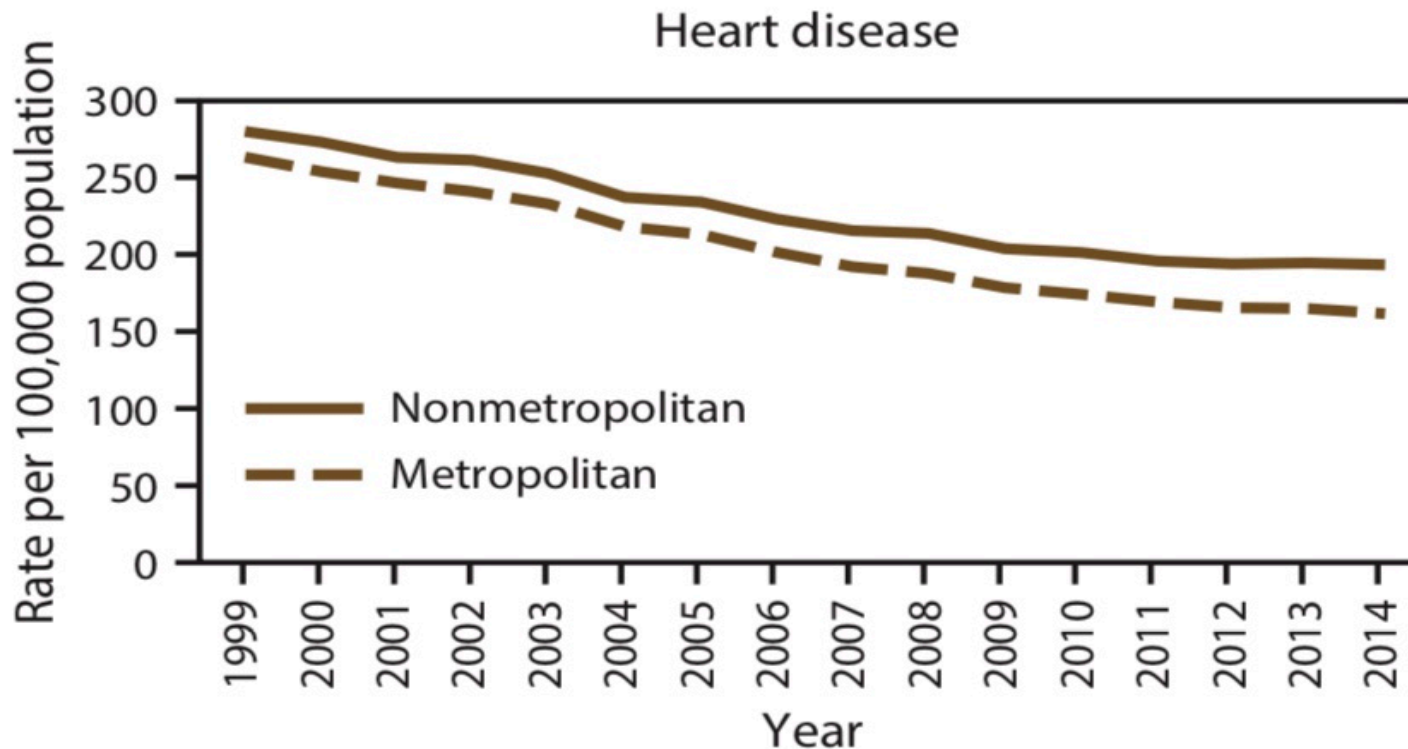
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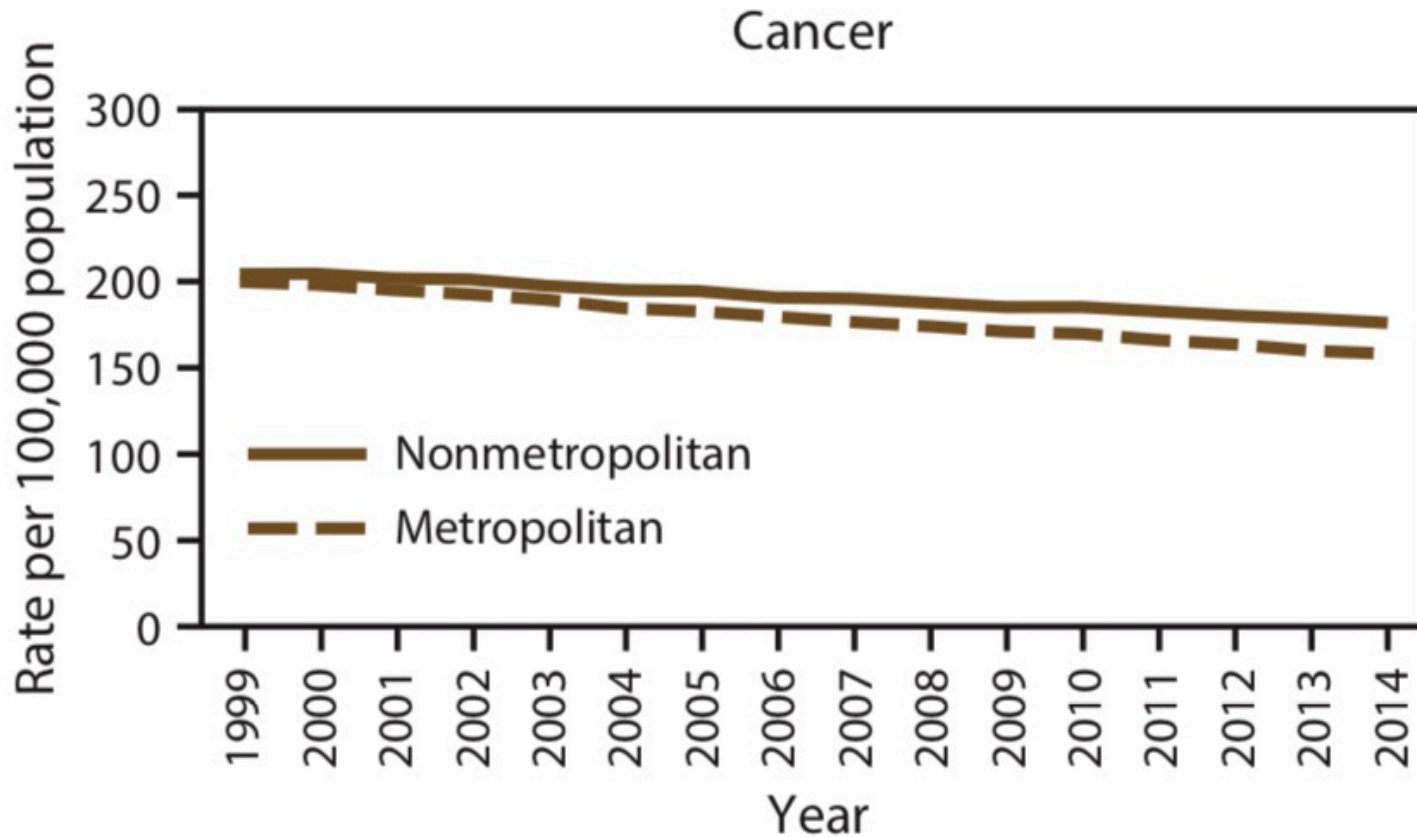
Mortality trends by leading causes of death

Deaths due to heart disease are declining more rapidly in Metro counties



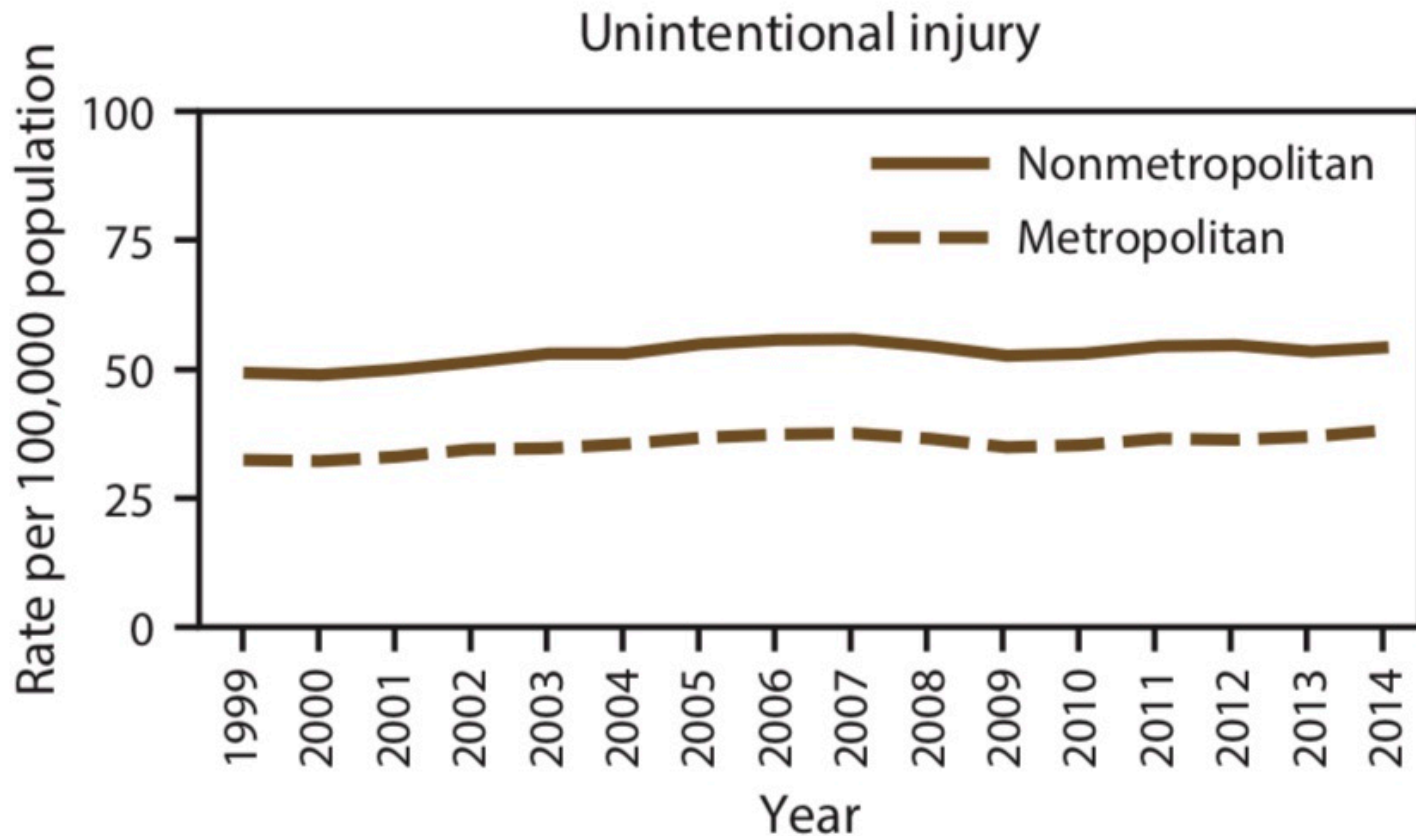
Mortality trends by leading causes of death

Deaths due to cancer are declining more rapidly in Metro counties



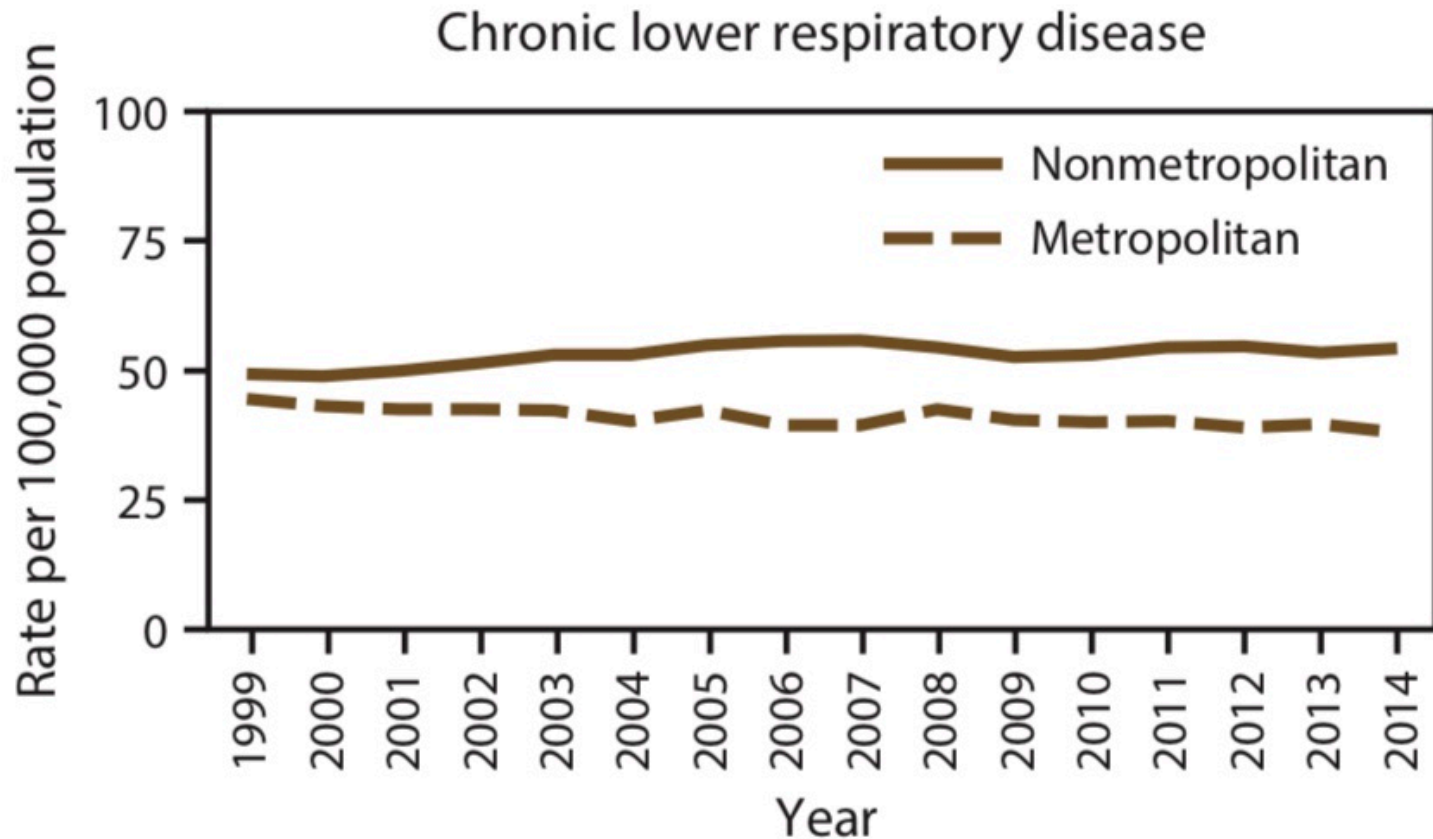
Mortality trends by leading causes of death

Deaths due to injury are consistently higher in rural areas



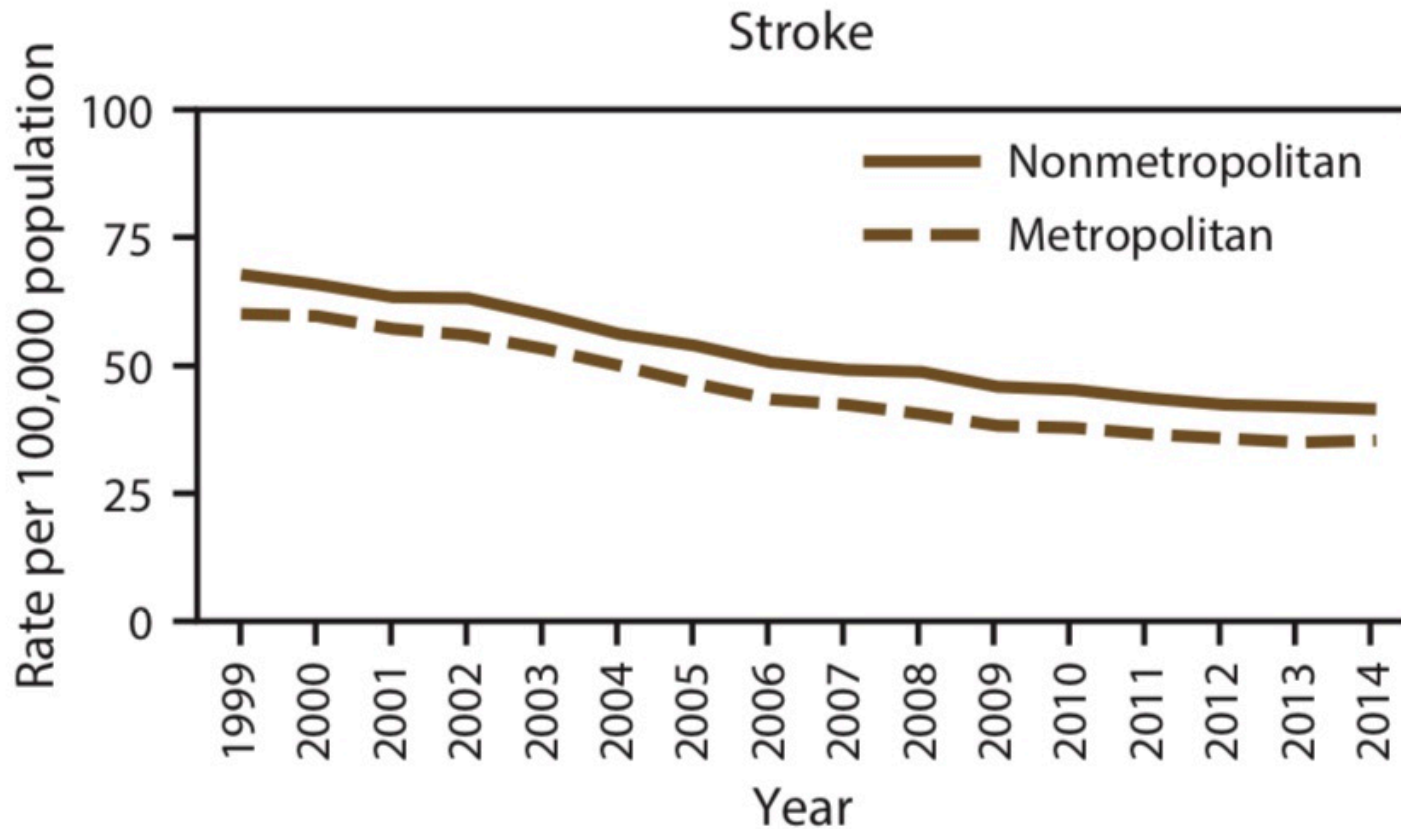
Mortality trends by leading causes of death

Deaths due to COPD, other lung disorders are declining more rapidly in Metro counties



Mortality trends by leading causes of death

Stroke deaths declining but still higher in rural



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Source: Moy et al 2017

SS6601

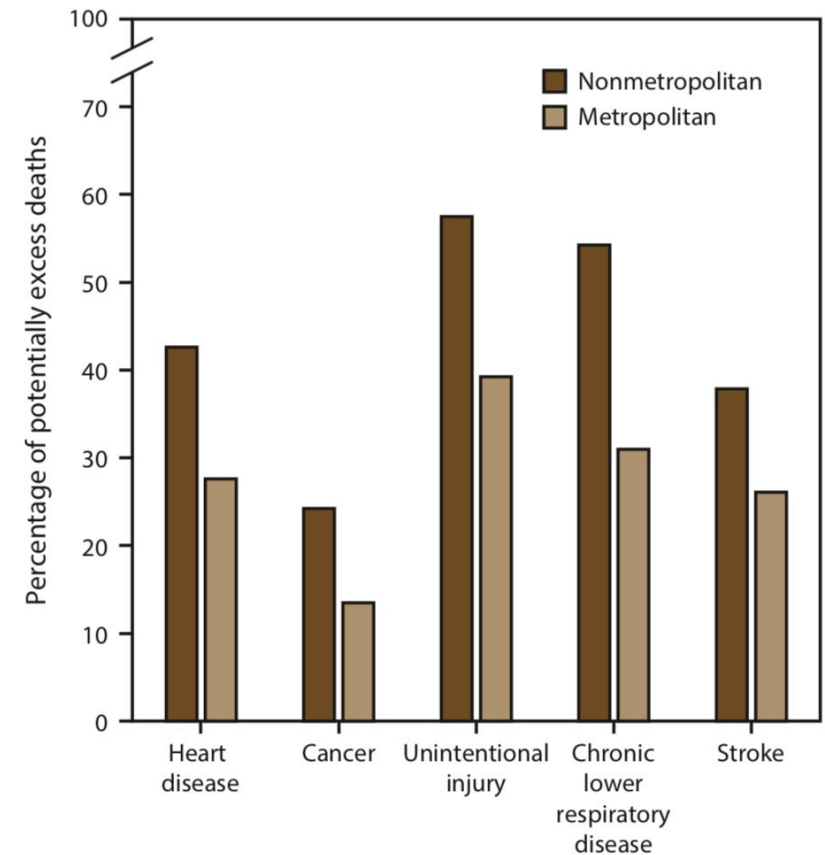


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“Excess” deaths: before age 80

Relative contributions of top causes of death to excess rural mortality

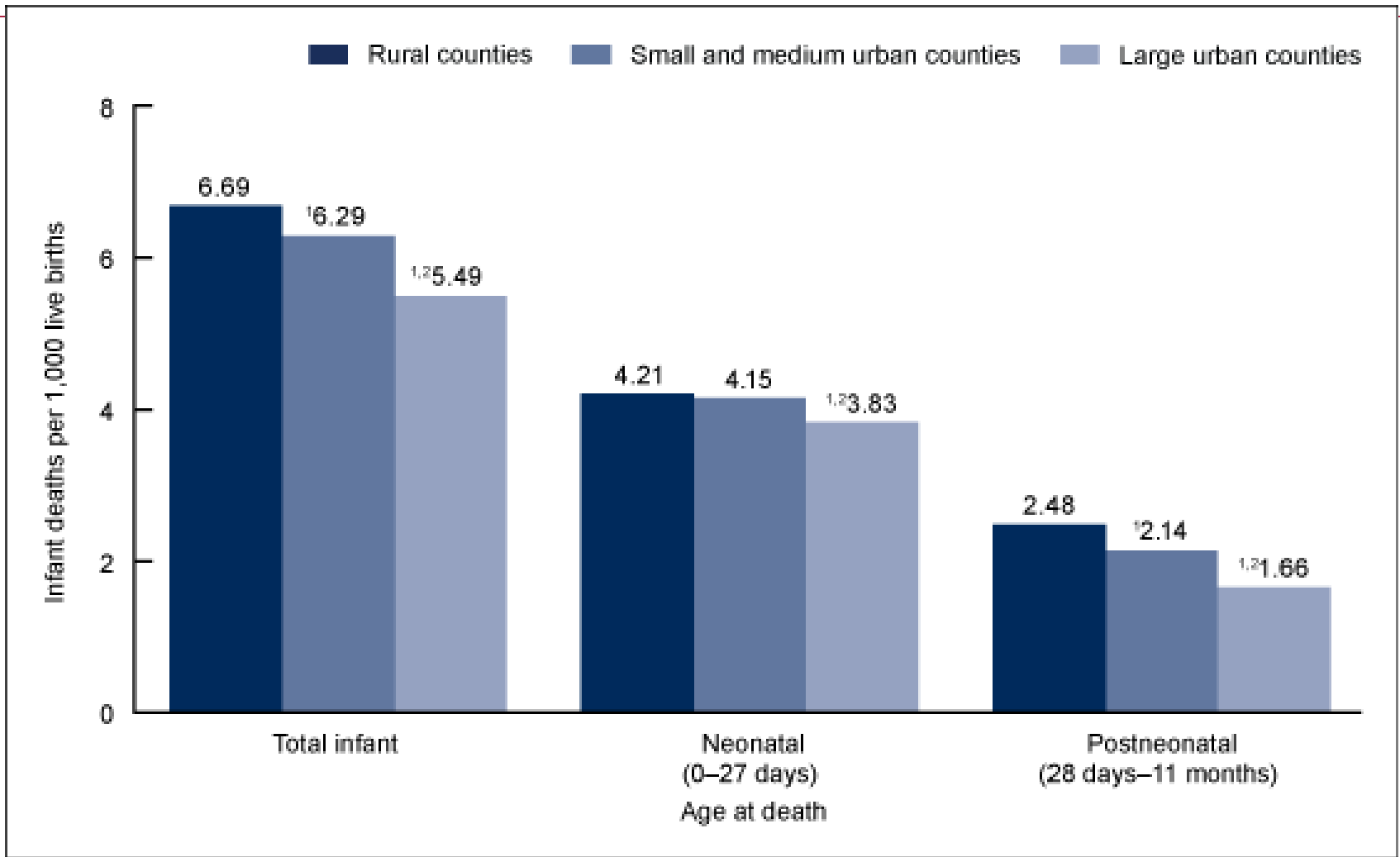
FIGURE 4. Percentage of potentially excess deaths* among persons aged <80 years for five leading causes of death in nonmetropolitan and metropolitan areas[†] — National Vital Statistics System, United States, 2014



Source: Moy et al 2017
SS6601



Infant mortality, 2013-2015



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NCJHS Data Brief No. 300, February 2016



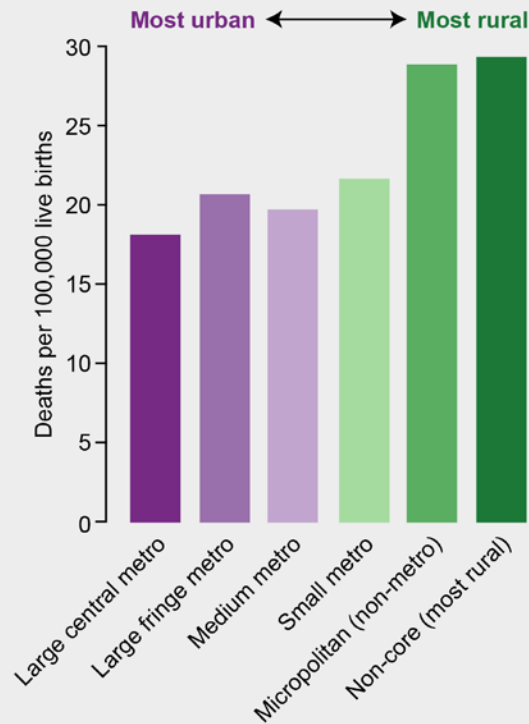
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Moms and Babies lost

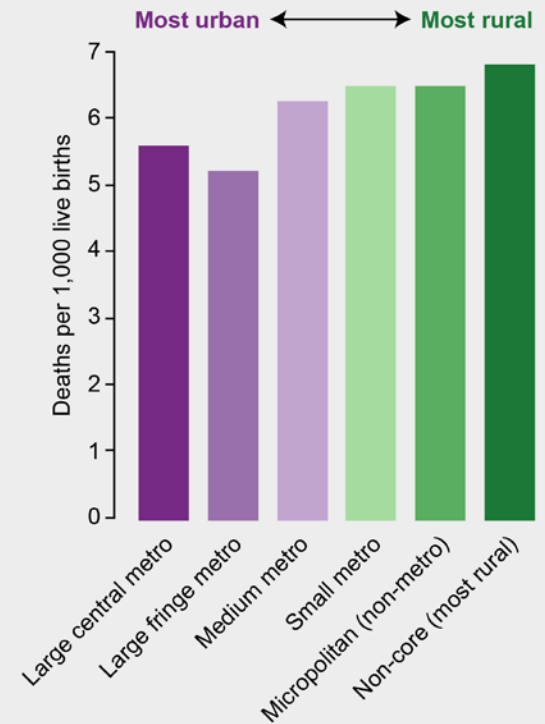
Maternal and Infant Mortality Rates Are Highest in Rural America

According to publicly available data from the U.S. Centers for Disease Control and Prevention analyzed by *Scientific American*, women living in rural areas of the U.S. have significantly higher chances of dying from causes related to pregnancy or childbirth compared with their city-dwelling counterparts. Likewise, babies are more likely to die before their first birthday if they live in rural locations. The graphs below reflect 2015 data.

Maternal Mortality Rates



Infant Mortality Rates



<https://www.scientificamerican.com/article/maternal-health-care-is-disappearing-in-rural-america/>



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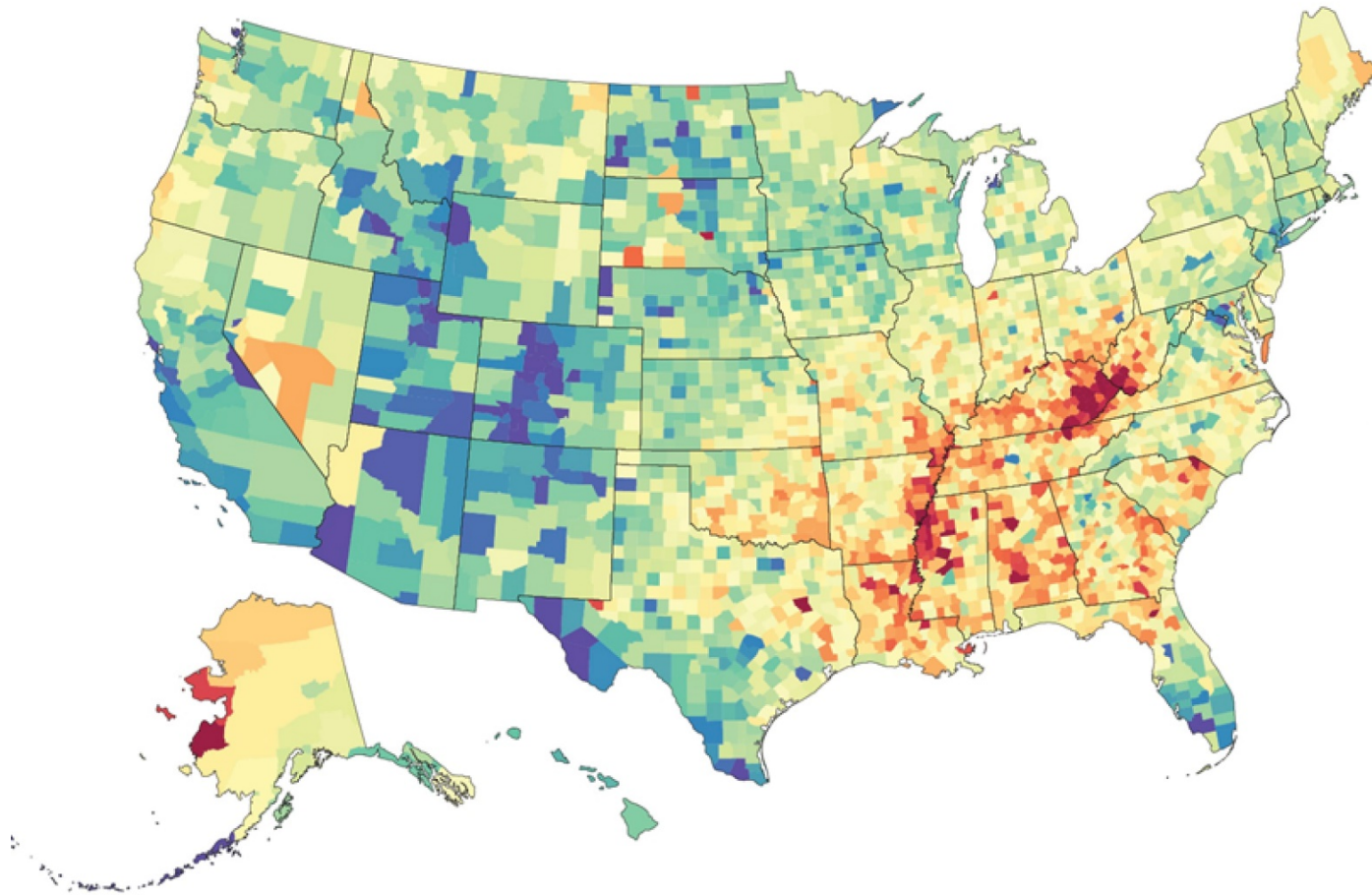
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Cancer is part of the problem....

A | Age-standardized mortality rate from neoplasms, both sexes, 2014



Deaths per 100 000 population

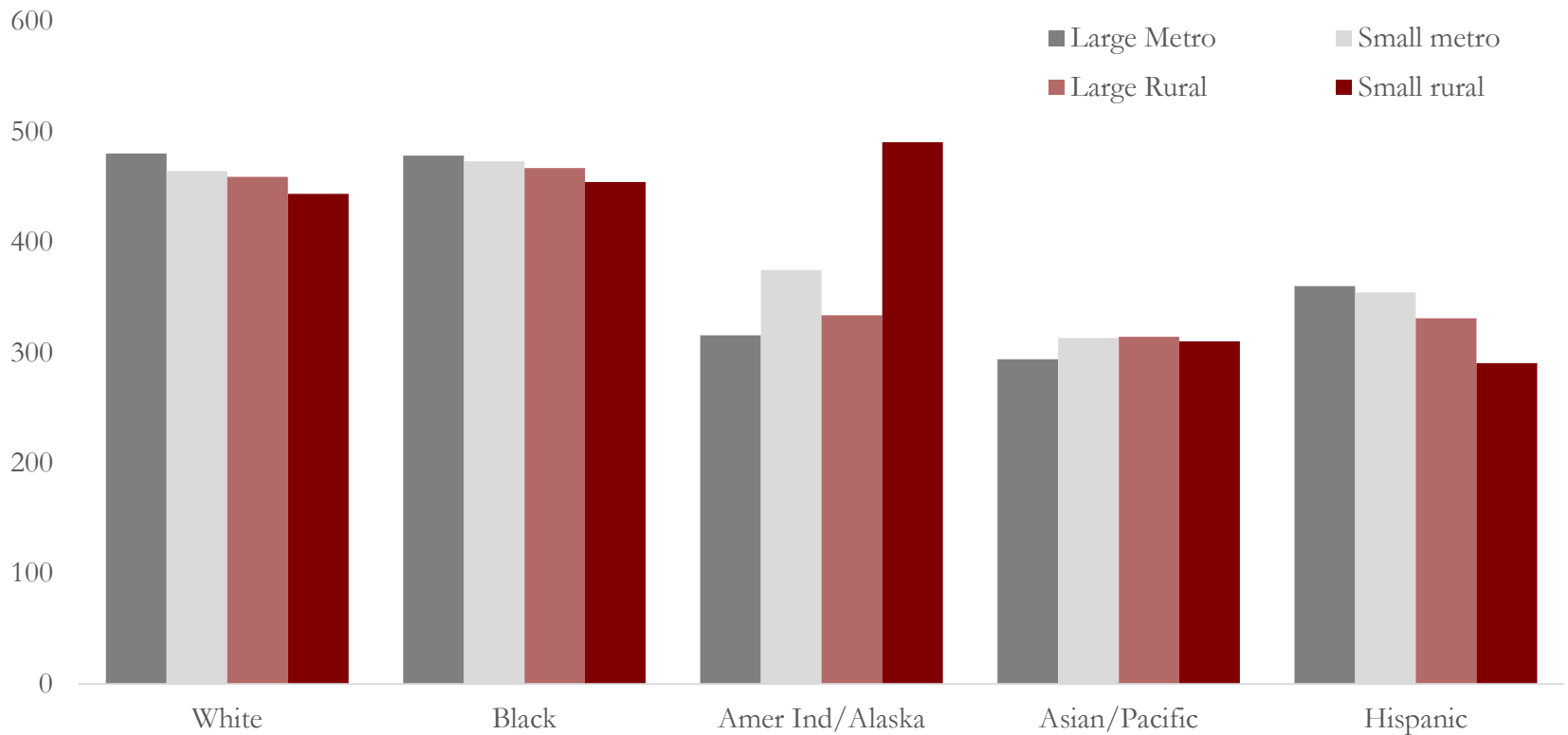


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Cancer incidence lower in rural

Cancer incidence rates, 2009-2013, by race/ethnicity and residence



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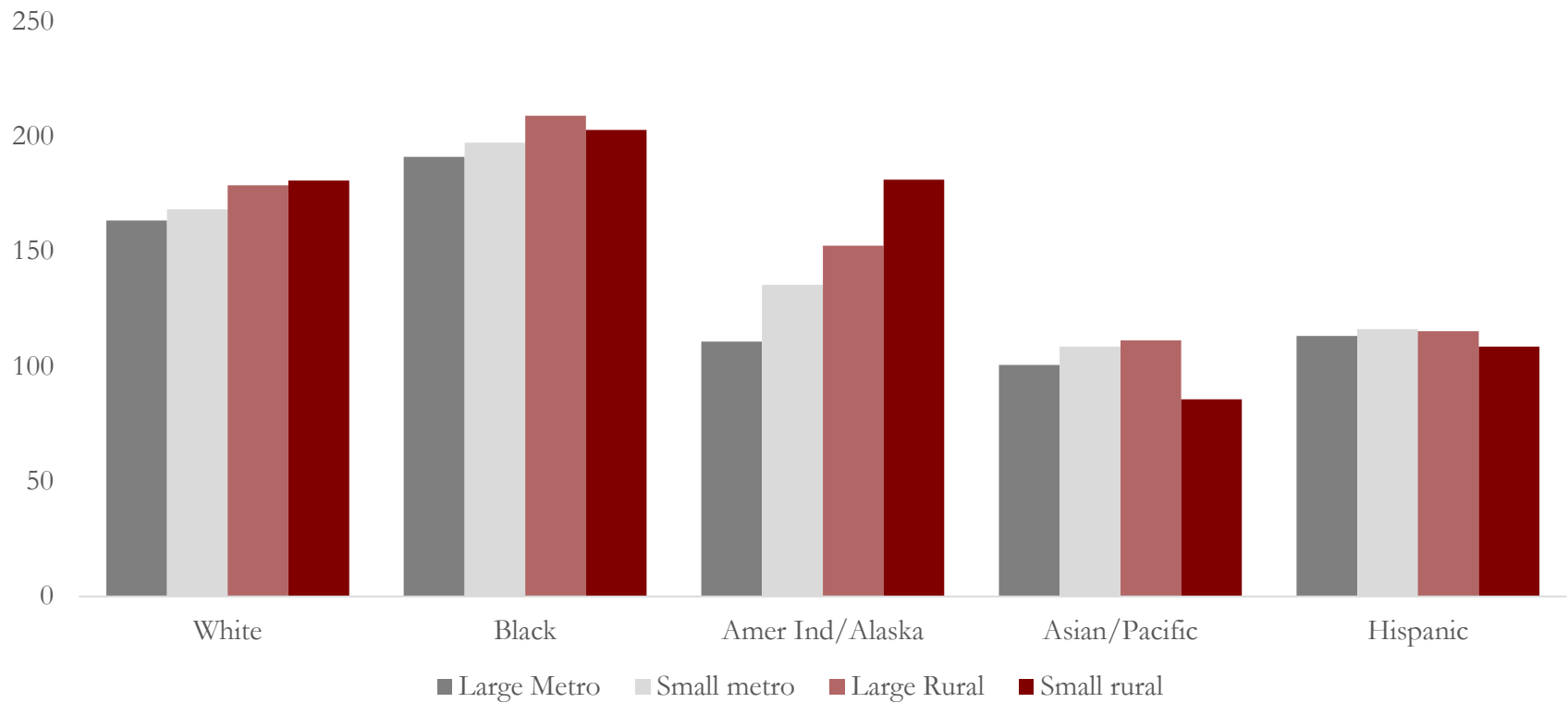
Rural Health Research Center Source: SS6614



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But death rates are higher in rural

Cancer Death Rates, 2011-2015, by race/ethnicity and residence



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Rural Health Research Center Source: SS6614



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Current issues in mortality

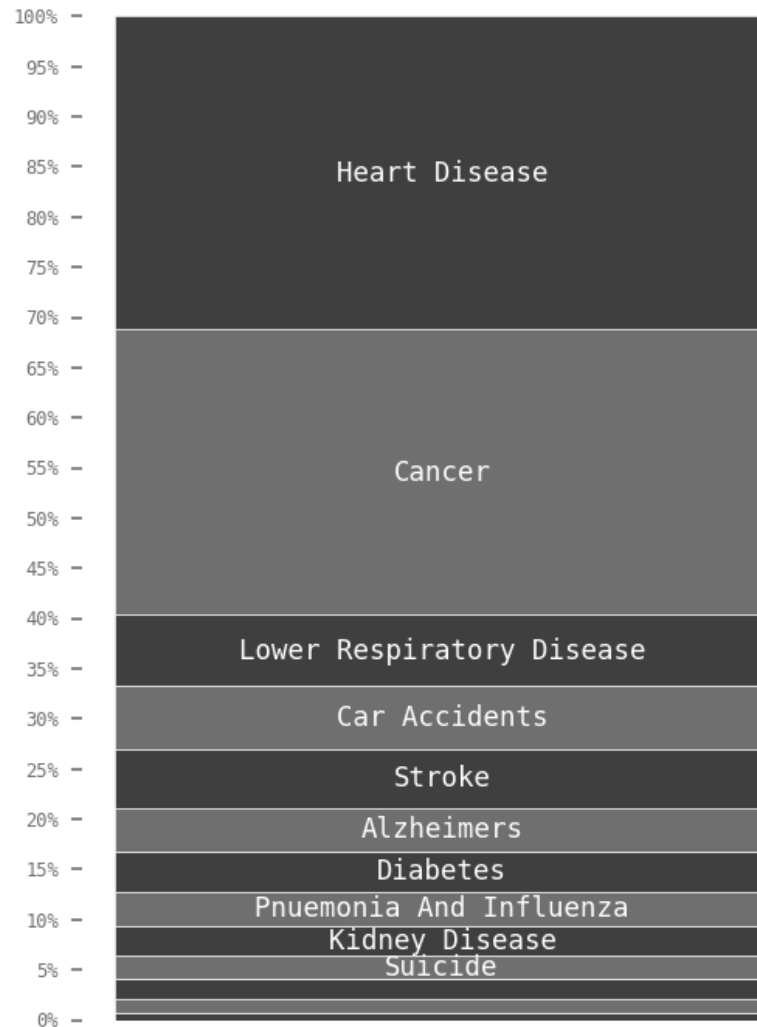
Kevin J. Bennett, Phd

Kevin.bennett@uscmed.sc.edu

@SCCRPHC @kevbosheth (unofficial)

CDC Cause of Death in USA

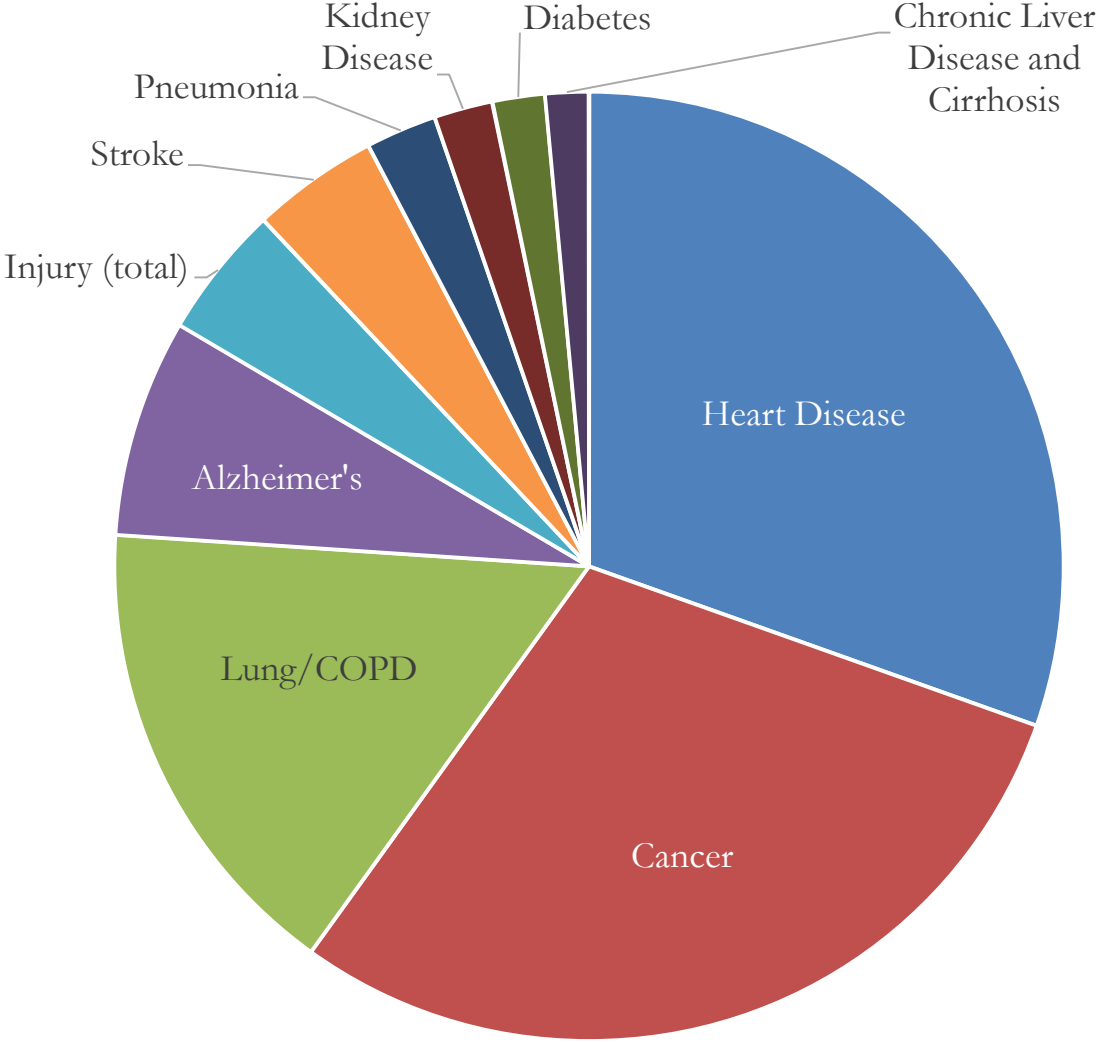
"What actually causes death?"



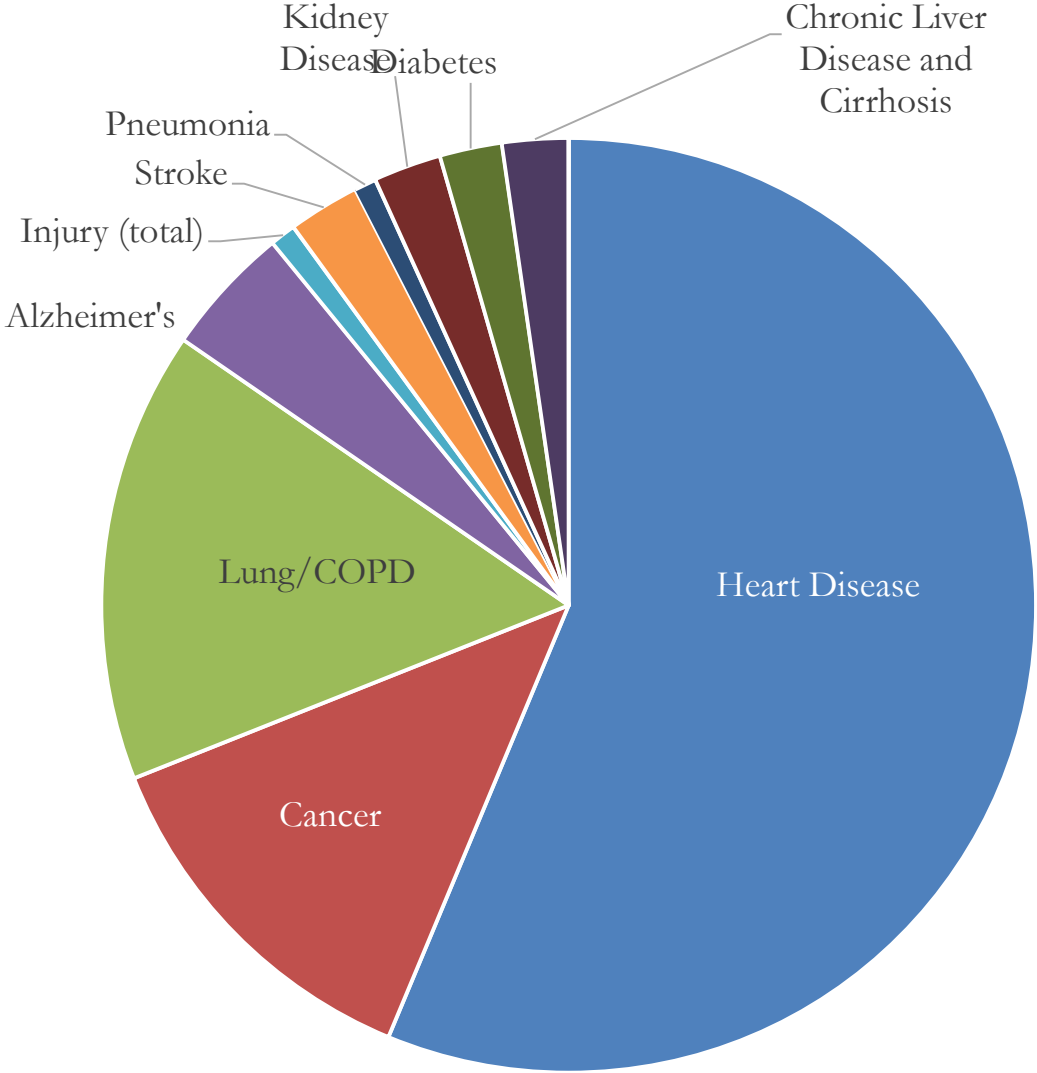
Data: CDC, Google, New York Times, The Guardian
Code: www.github.com/aaronpenne
Twitter: @aaronpenne
Aaron Penne © 2018

Based on in-depth analysis by H. Al-Jamaly, M. Siemers,
O. Shen, and N. Stone at owenshen24.github.io/charting-death

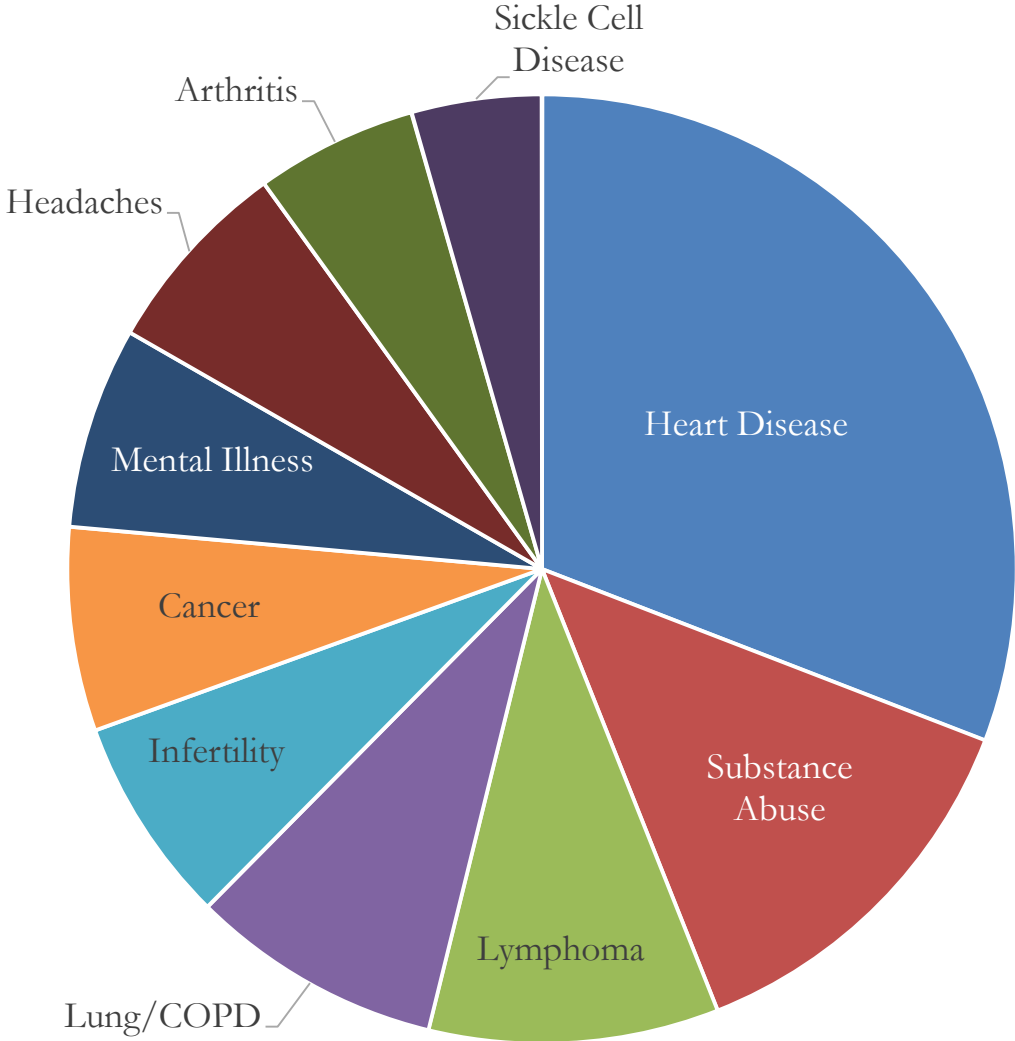
Top 10 Causes of Death



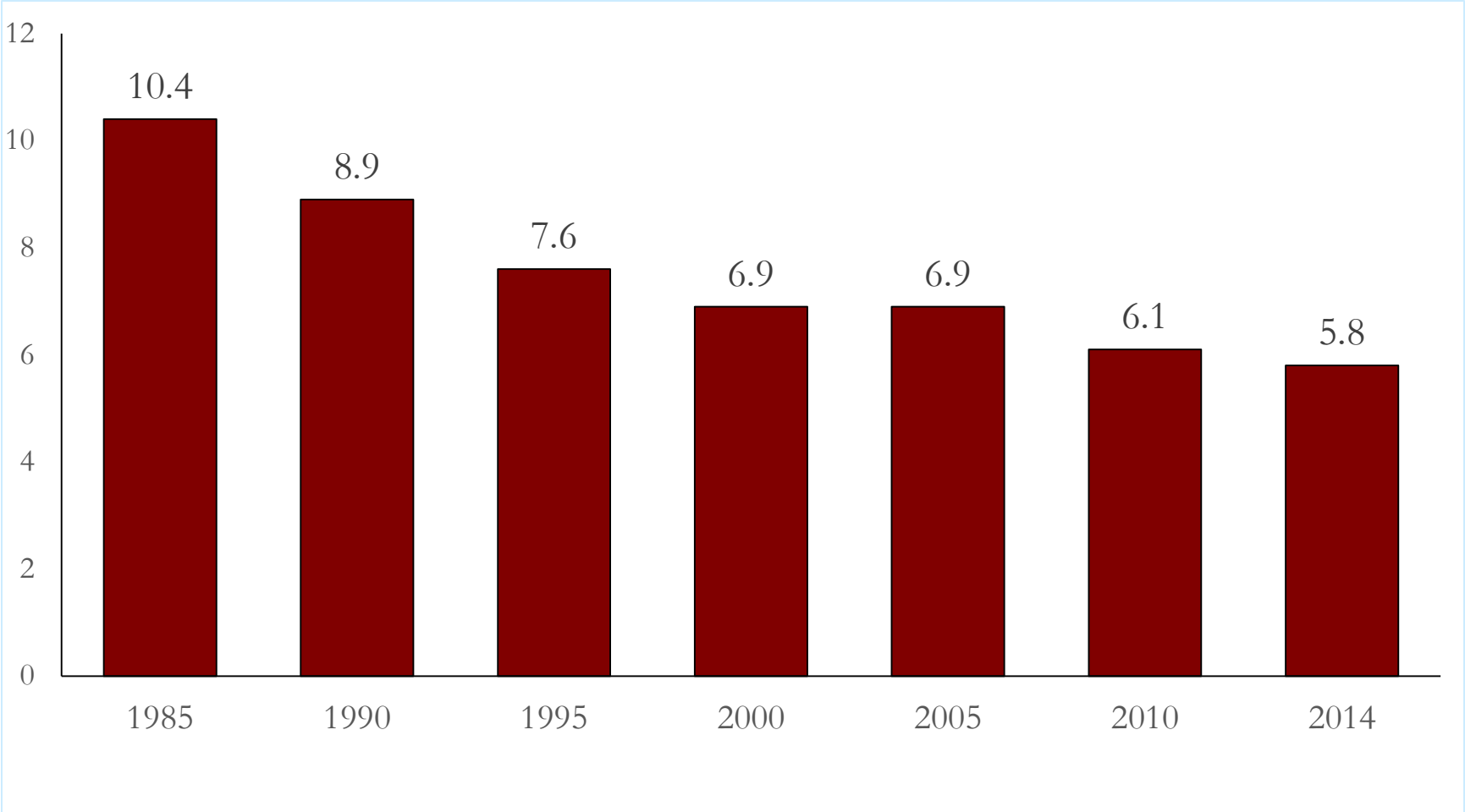
Top 10 Causes of Death, % NIH Funding



Top 10 by NIH Funding %



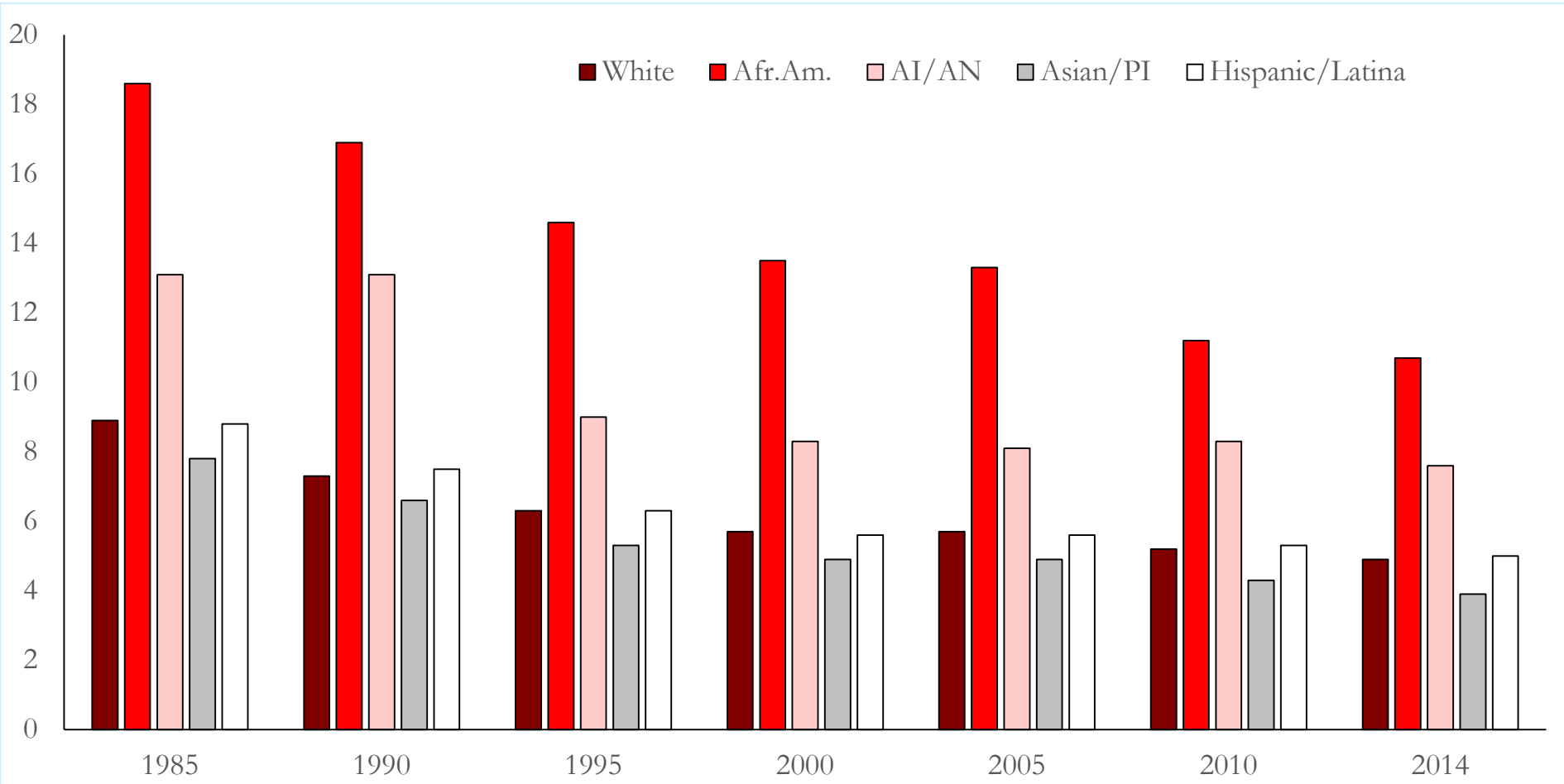
Infant Mortality - US



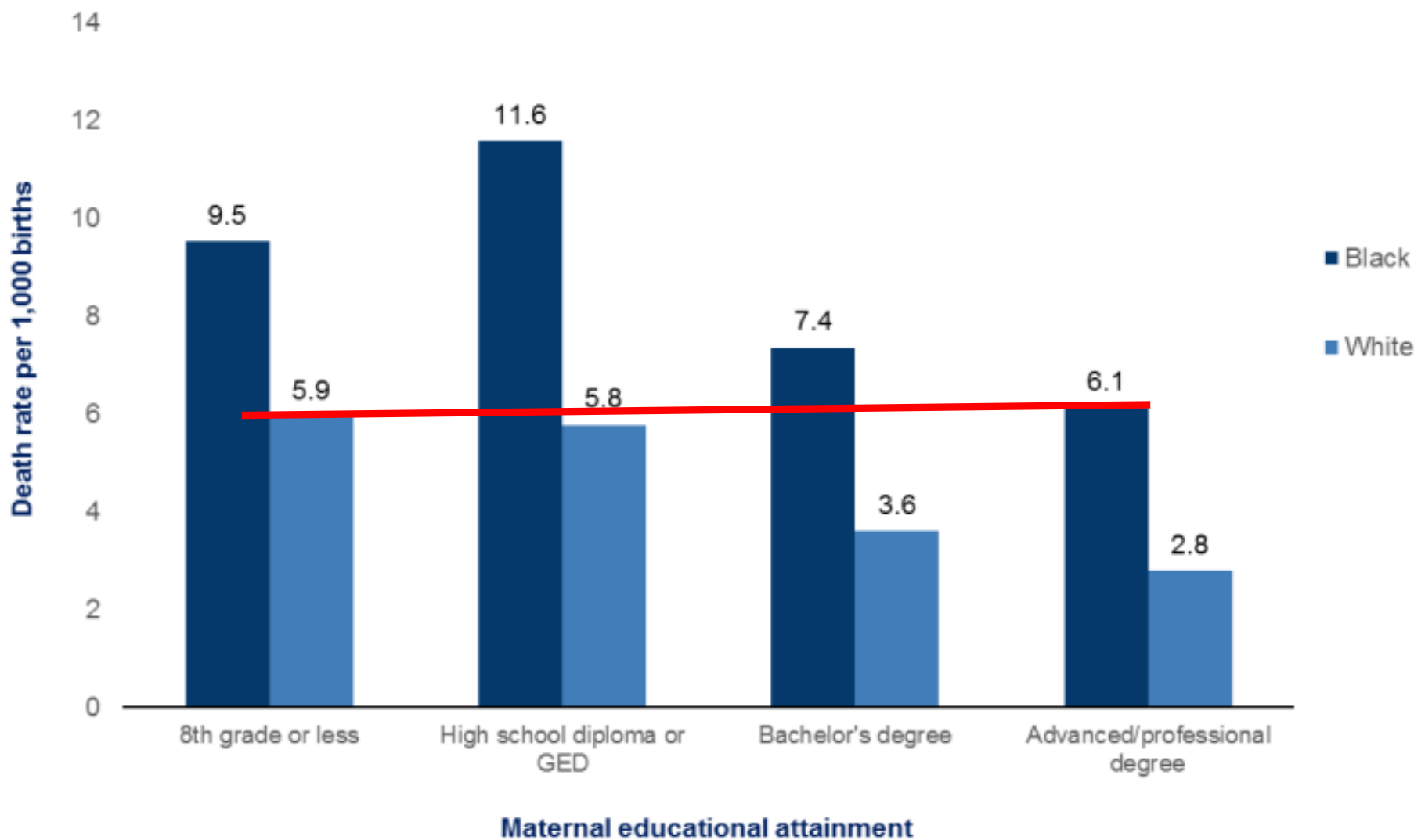
Infant Mortality Rates, 2016

1 Monaco	1.8	31 Lithuania	3.8
2 Japan	2	32 Denmark	4
3 Iceland	2.1	33 European Union	4
4 Singapore	2.4	34 Slovenia	4
5 Bermuda	2.5	35 Isle of Man	4.1
6 Finland	2.5	36 Australia	4.3
7 Norway	2.5	37 Liechtenstein	4.3
8 Czech Republic	2.6	38 United Kingdom	4.3
9 Sweden	2.6	39 Portugal	4.4
10 Hong Kong	2.7	40 San Marino	4.4
11 Korea, South	3	41 Taiwan	4.4
12 Macau	3.1	42 Wallis and Futuna	4.4
13 France	3.3	43 Cuba	4.5
14 Italy	3.3	44 New Zealand	4.5
15 Spain	3.3	45 Poland	4.5
16 Anguilla	3.4	46 Canada	4.6
17 Austria	3.4	47 Greece	4.6
18 Belgium	3.4	48 French Polynesia	4.7
19 Germany	3.4	49 Hungary	5
20 Guernsey	3.4	50 Slovakia	5.2
21 Luxembourg	3.4	51 Guam	5.3
22 Israel	3.5	52 Latvia	5.3
23 Malta	3.5	53 New Caledonia	5.3
24 Andorra	3.6	54 Northern Mariana Islands	5.3
25 Belarus	3.6	55 Faroe Islands	5.5
26 Netherlands	3.6	56 Bosnia and Herzegovina	5.6
27 Switzerland	3.6	57 United States	5.8
28 Ireland	3.7	58 Serbia	5.9
29 Estonia	3.8	59 Cayman Islands	6
30 Jersey	3.8	60 Gibraltar	6

Infant Mortality – US, by Race/ ethnicity



Infant mortality higher for middle-class blacks than lower-class whites



Source: Centers for Disease Control and Prevention (Wonder), Linked Birth / Infant Death Records, 2007 - 2013.

BROOKINGS

Infant Mortality, by State, 2016

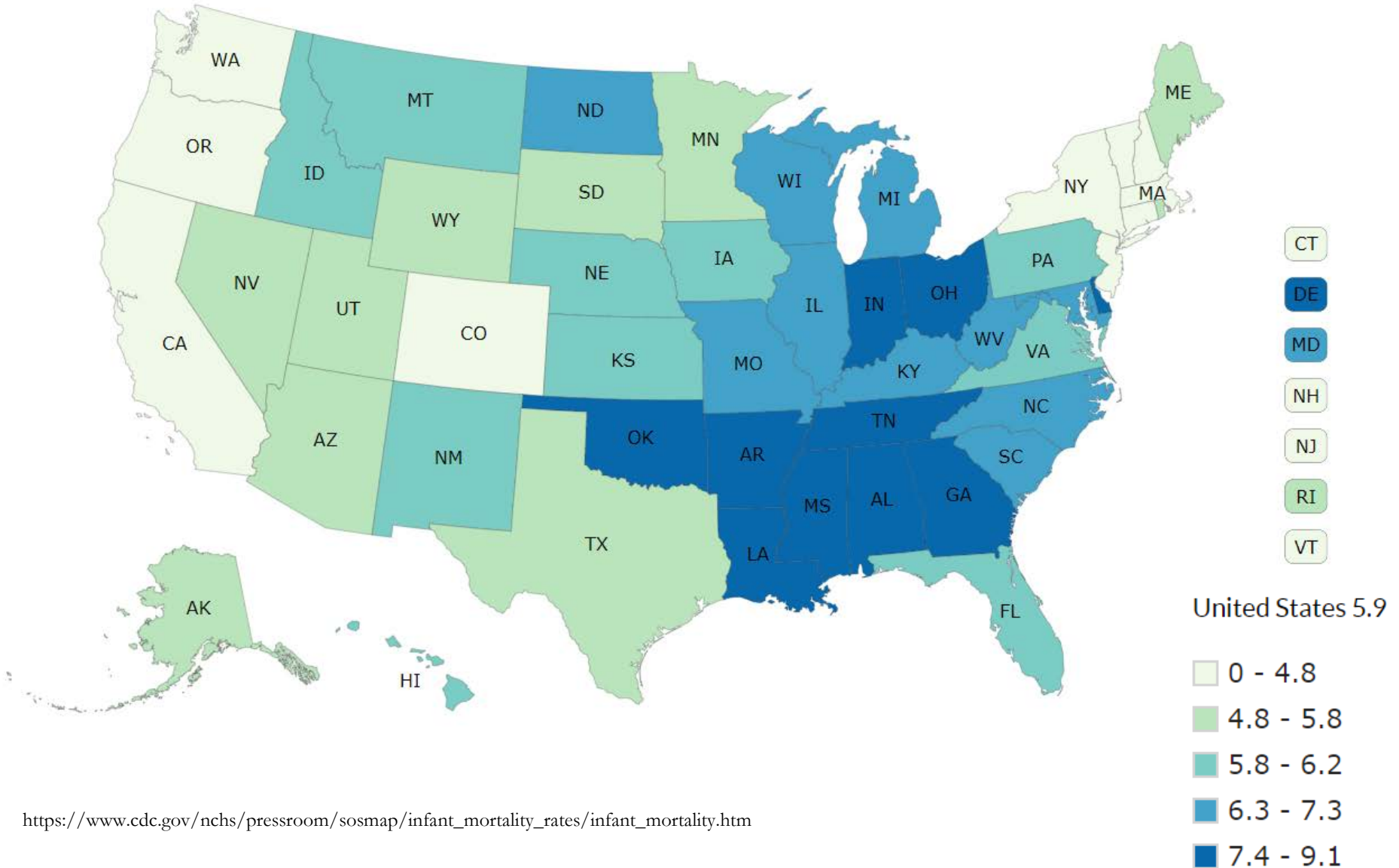
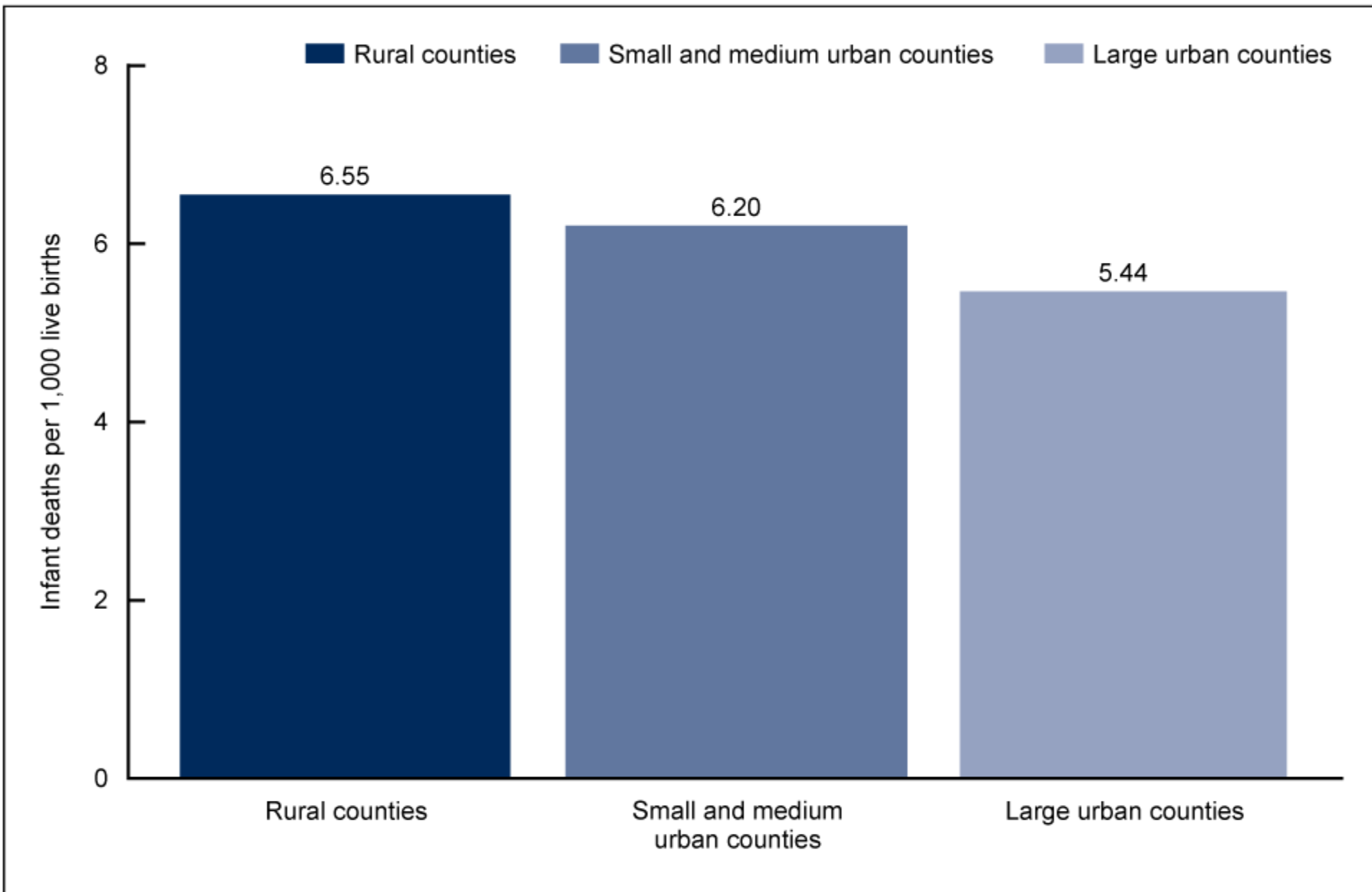


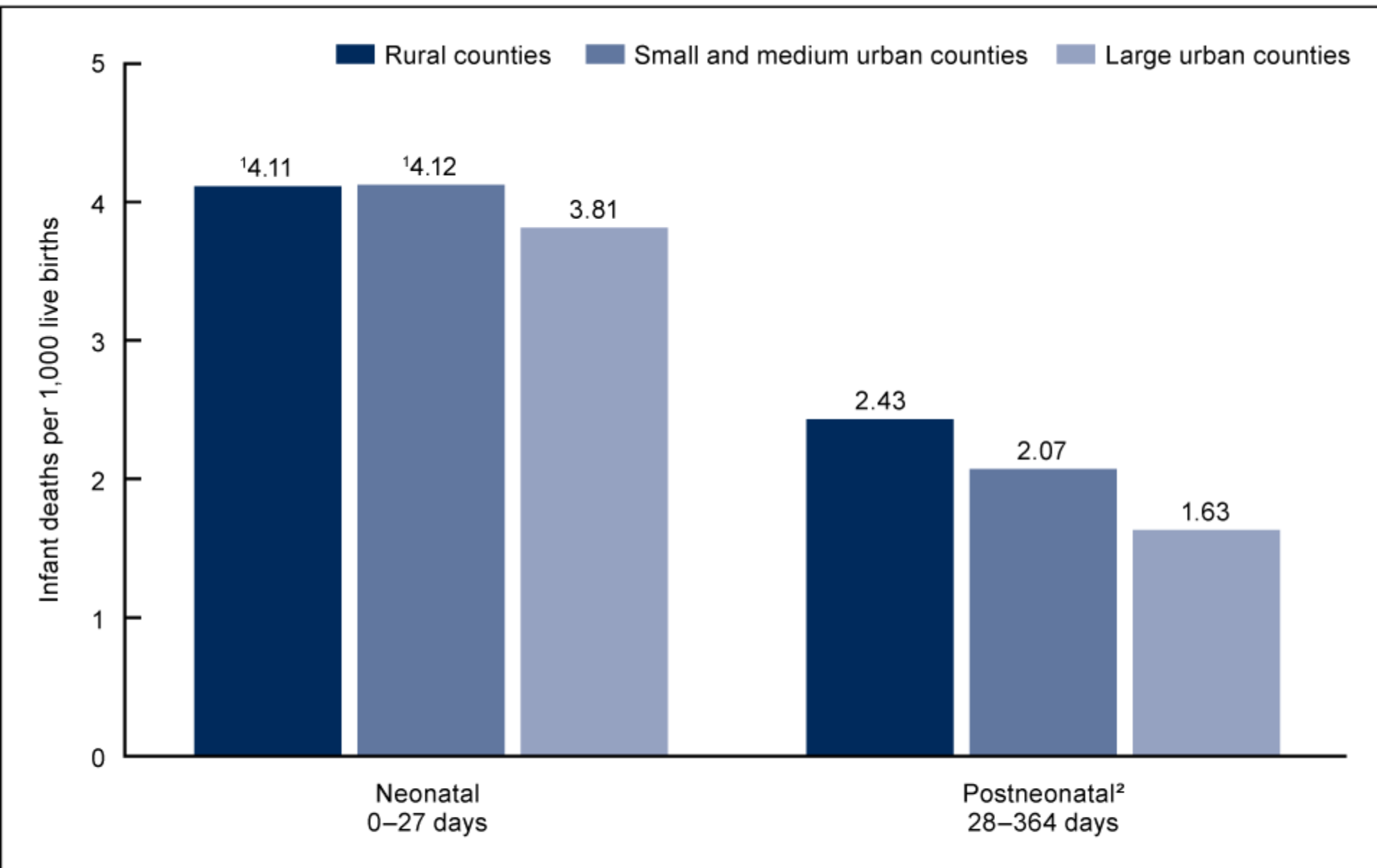
Figure 1. Infant mortality rates, by urbanization level: United States, 2014



NOTES: Significant decreasing linear trend from rural counties to large urban counties ($p < 0.05$). County designation is based on mother's county of residence. County classification is based on 2013 NCHS Urban–Rural Classification Scheme for Counties. Access data table for Figure 1 at: https://www.cdc.gov/nchs/data/databriefs/db285_table.pdf#1.

SOURCE: NCHS, National Vital Statistics System.

Figure 2. Infant mortality rates, by urbanization level and infant age at death: United States, 2014



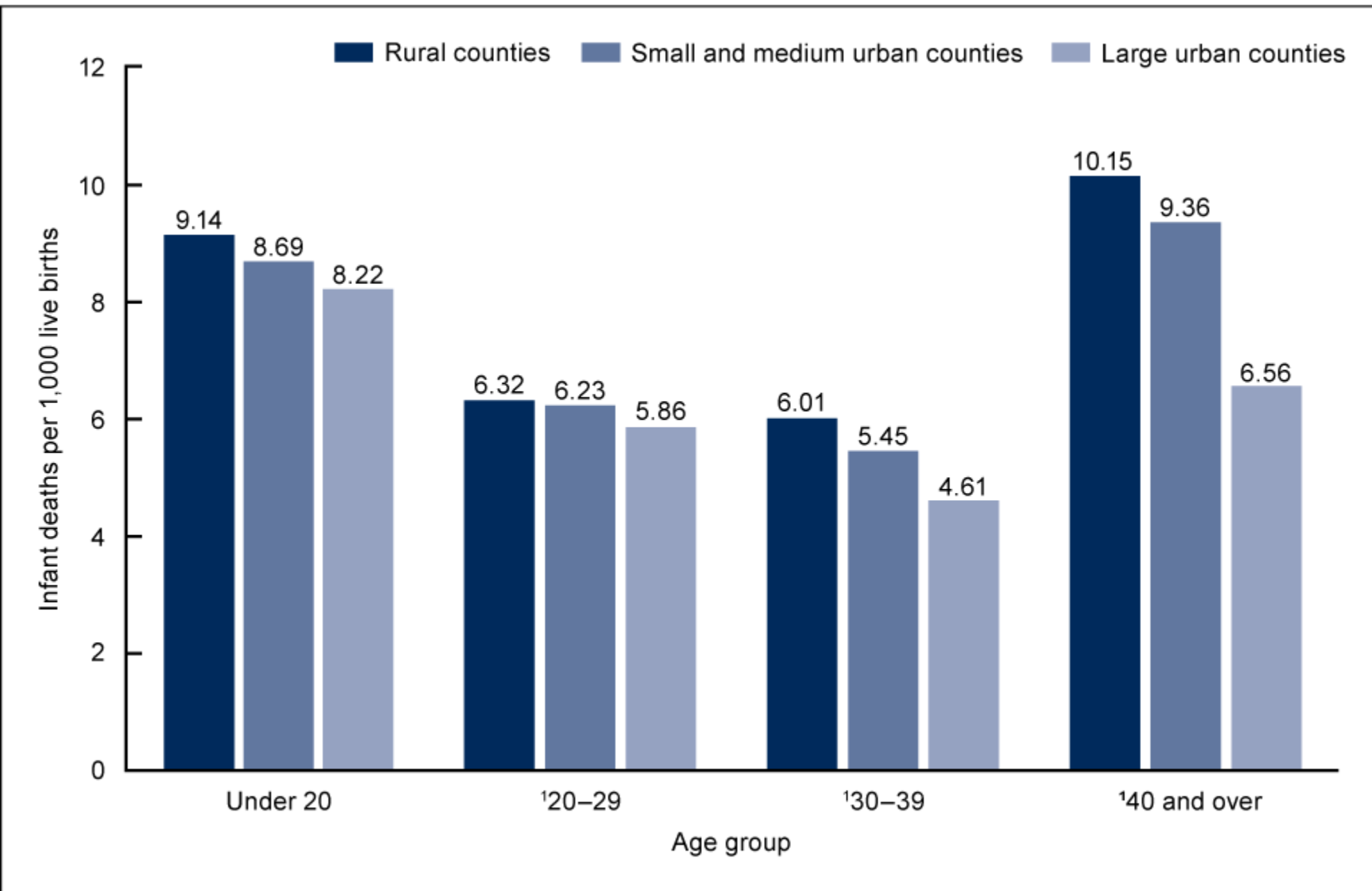
¹Significantly different from large urban counties ($p < 0.05$).

²Significant decreasing linear trend from rural counties to large urban counties ($p < 0.05$).

NOTES: County designation is based on mother's county of residence. County classification is based on 2013 NCHS Urban-Rural Classification Scheme for Counties. Access data table for Figure 2 at: https://www.cdc.gov/nchs/data/databriefs/db285_table.pdf#2.

SOURCE: NCHS, National Vital Statistics System.

Figure 3. Infant mortality rates, by urbanization level and age of mother: United States, 2014

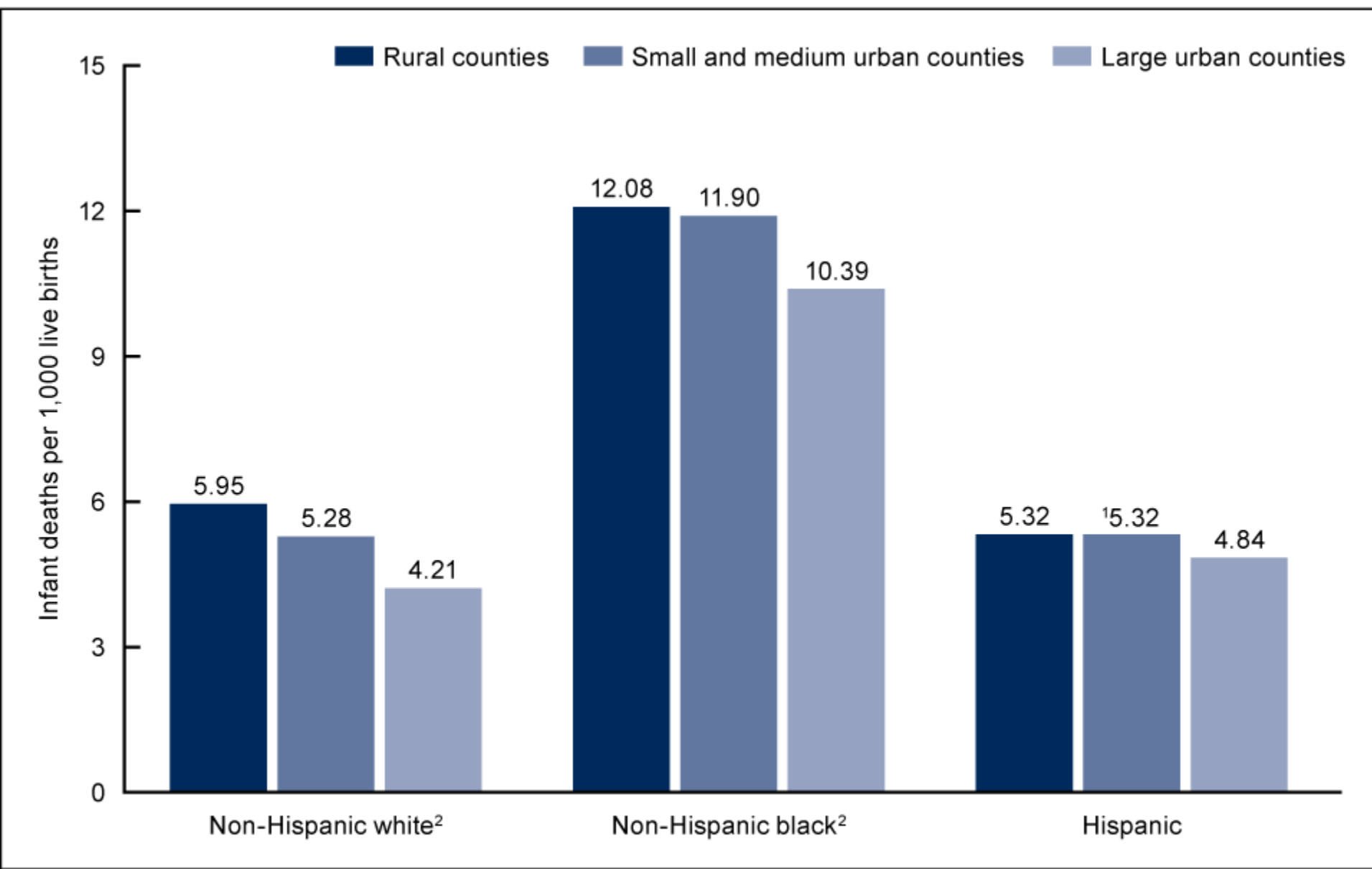


¹Significant decreasing linear trend from rural counties to large urban counties ($p < 0.05$).

NOTES: County designation is based on mother's county of residence. County classification is based on 2013 NCHS Urban-Rural Classification Scheme for Counties. Access data table for Figure 3 at: https://www.cdc.gov/nchs/data/databriefs/db285_table.pdf#3.

SOURCE: NCHS, National Vital Statistics System.

Figure 4. Infant mortality rates, by urbanization level and race and Hispanic origin of mother: United States, 2014



¹Significantly different from large urban counties ($p < 0.05$).

²Significant decreasing linear trend from rural counties to large urban counties ($p < 0.05$).

NOTES: County designation is based on mother's county of residence. County classification is based on the 2013 NCHS Urban-Rural Classification Scheme for Counties. Access data table for Figure 4 at: https://www.cdc.gov/nchs/data/databriefs/db285_table.pdf#4.

SOURCE: NCHS, National Vital Statistics System.

Serena Williams on Motherhood, Marriage, and Making Her Comeback

JANUARY 10, 2018 8:00 AM

by ROB HASKELL | *photographed by* MARIO TESTINO

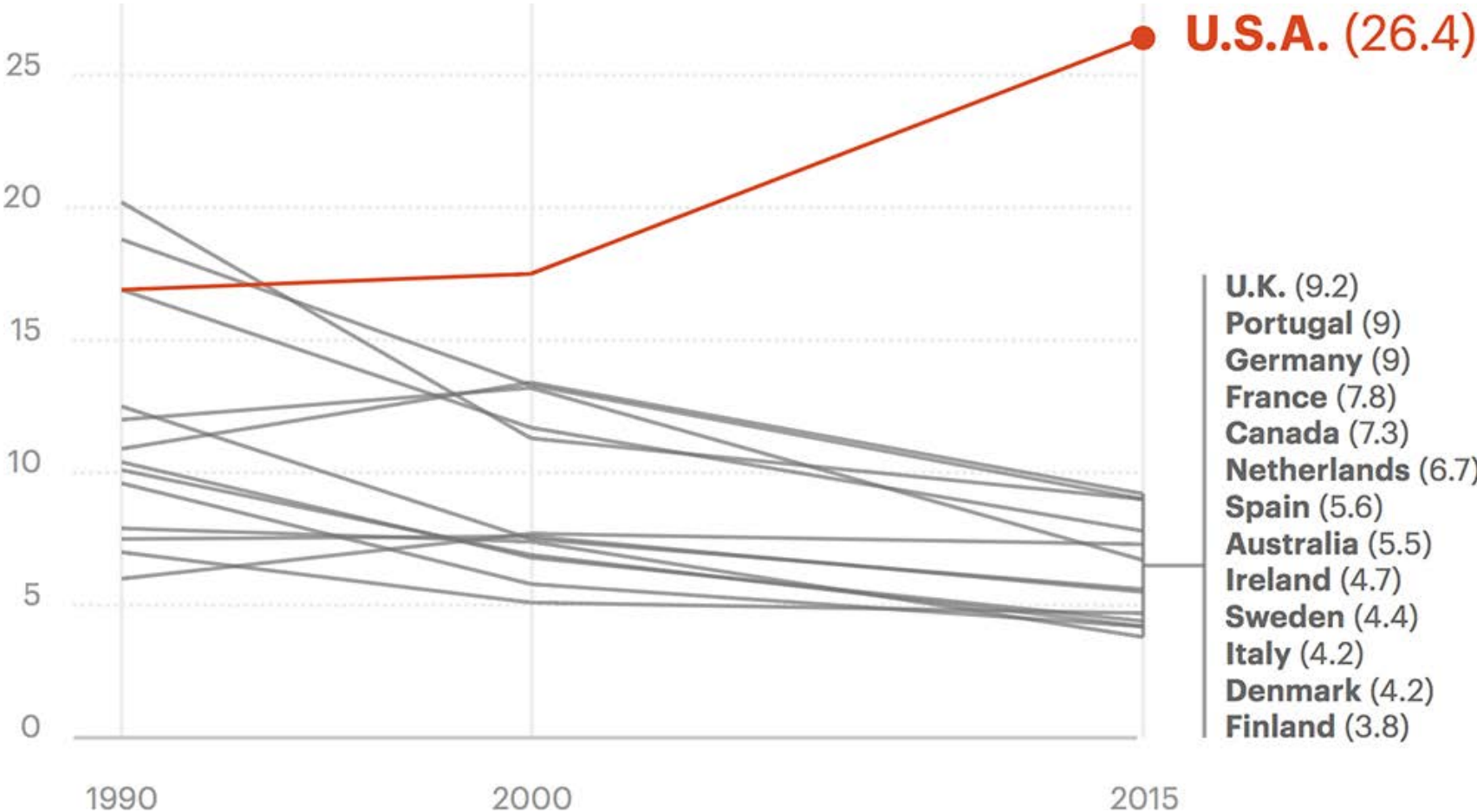
The Last Person You'd Expect to Die in Childbirth

The U.S. has the worst rate of maternal deaths in the developed world, and 60 percent are preventable. The death of Lauren Bloomstein, a neonatal nurse, in the hospital where she worked illustrates a profound disparity: The health care system focuses on babies but often ignores their mothers.

*by Nina Martin, ProPublica, and Renee Montagne, NPR
May 12, 2017*

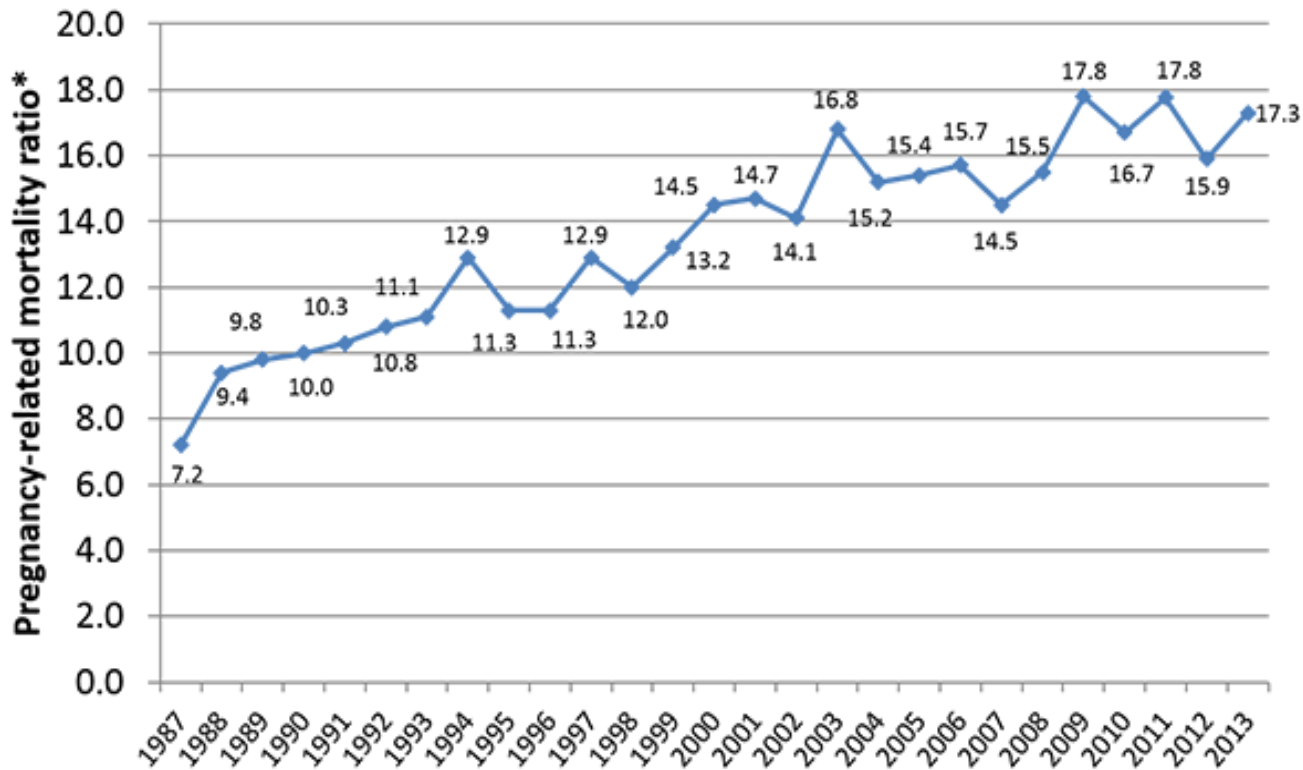
This story was co-published with NPR.

Maternal Death Rates, by year



Pregnancy-Related Mortality

Trends in pregnancy-related mortality
in the United States: 1987–2013



12.7 per 100,000
live births for white
women.

43.5 per 100,000
live births for black
women.

14.4 per 100,000
live births for
women of other
races.

*Note: Number of pregnancy-related deaths per 100,000 live births per year.

Rural America's Childbirth Crisis: The Fight to Save Whitney Brown

Women in sparsely populated places are more likely to die from pregnancy-related complications than those in large cities—a reversal from 2000

By *Betsy McKay* and *Paul Overberg*

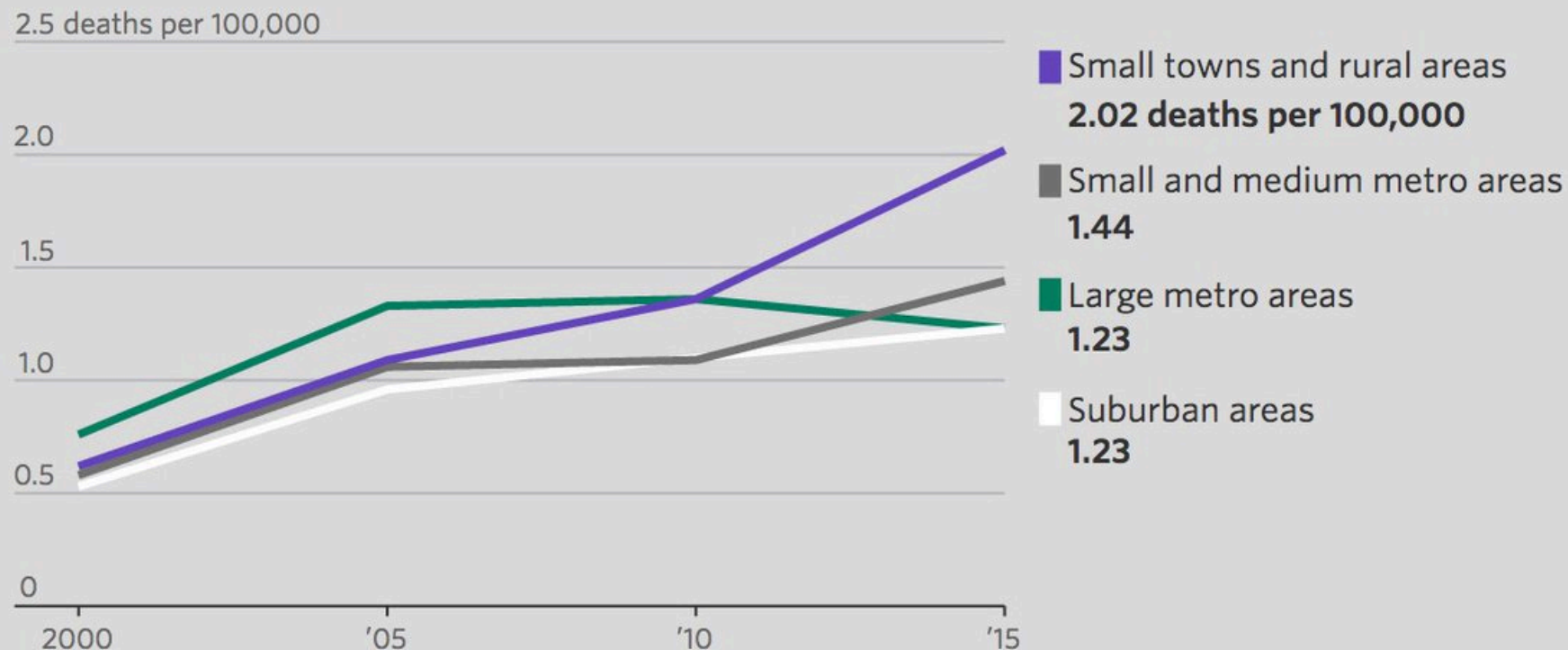
Aug. 11, 2017 10:42 a.m. ET

“The rate at which women died of pregnancy-related complications was 64% higher in rural areas than in large U.S. cities in 2015. That is a switch from 2000, when the rate in the cities was higher”

Family Tragedy

More women are dying during pregnancy and from post-natal complications than 15 years ago, and rates have risen the most for women in rural areas.

Maternal death rate per 100,000 women age 15 to 44*



Note: Large metropolitan areas are core counties of metro areas with more than 1 million people. Suburban areas are the other counties in those metros. Medium or small metropolitan areas are anchored by a city of at least 50,000. The remaining counties are small towns and rural areas.

*Rates standardized to match U.S. population profile in 2000, which improves comparisons across years by removing shifts in the population's age structure

Source: Centers for Disease Control and Prevention

Why is rural different?

Vox

EXPLAINERS POLITICS & POLICY WORLD CULTURE SCIENCE & HEALTH IDENTITIES MORE ▾

Urban and rural America are different worlds. Sort of.

NEWS > NATION WORLD NEWS

New poll of rural Americans shows deep cultural divide with urban centers

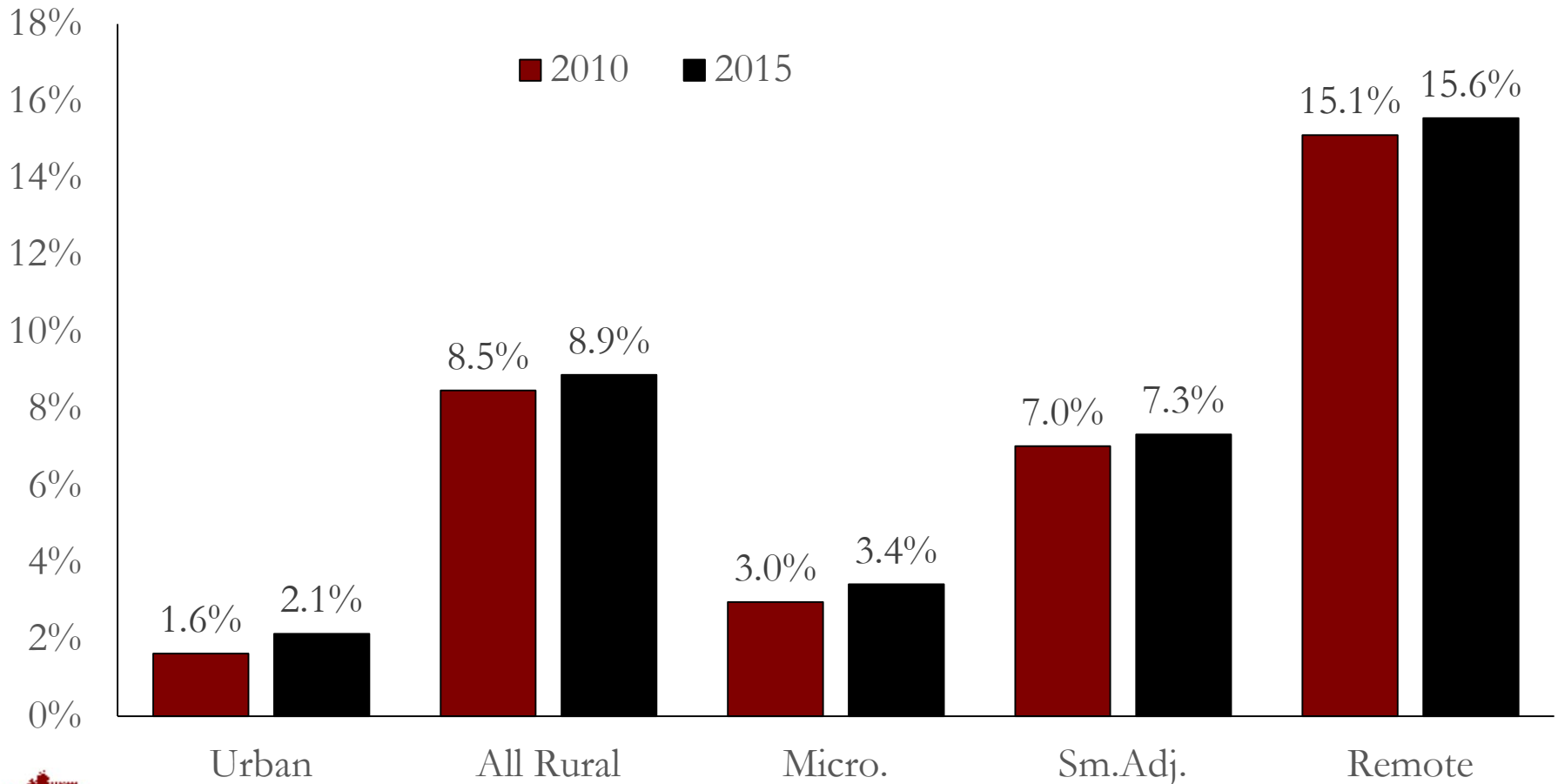
It's not elites vs. populists. It's cities vs. the countryside.



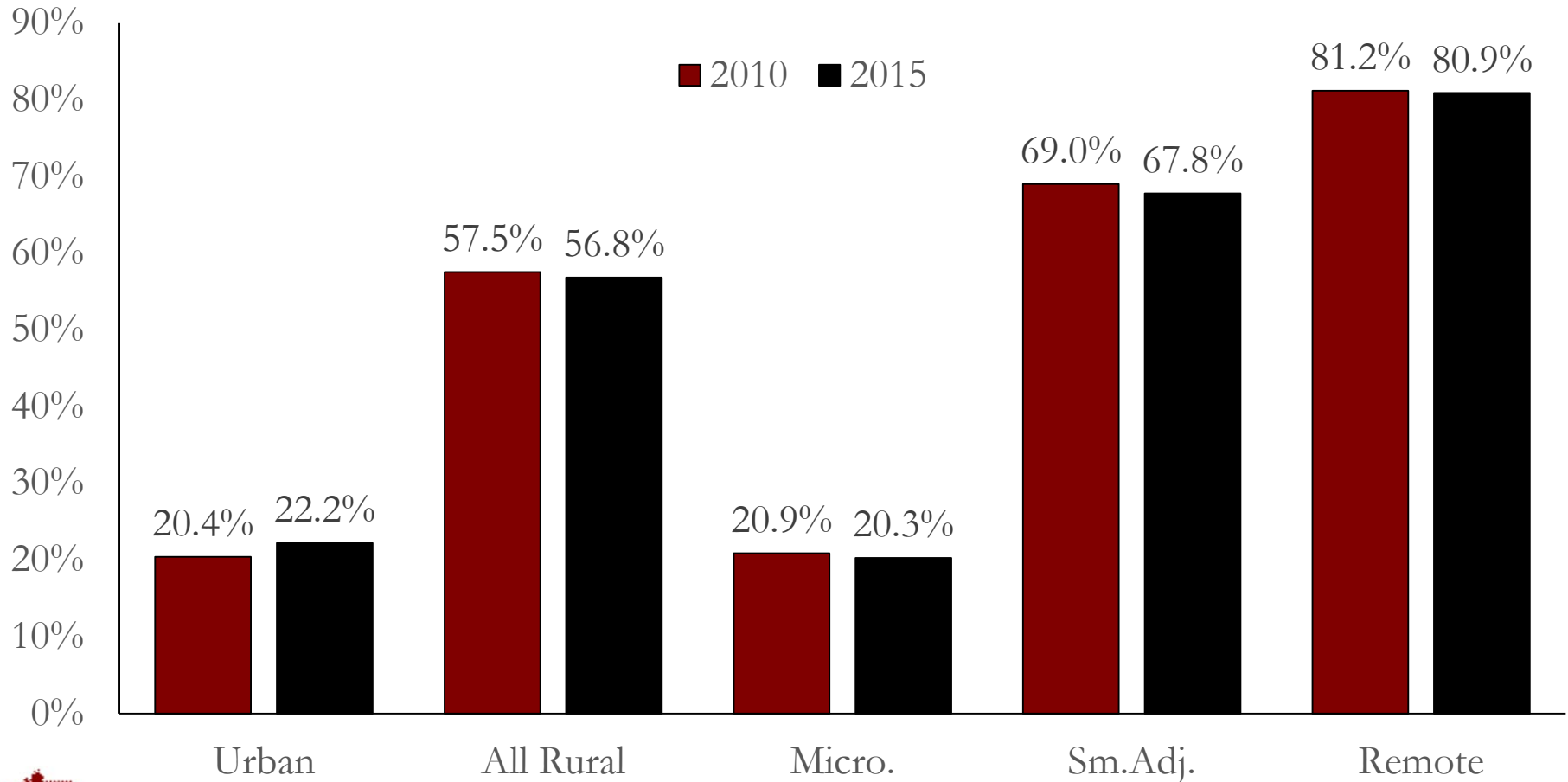
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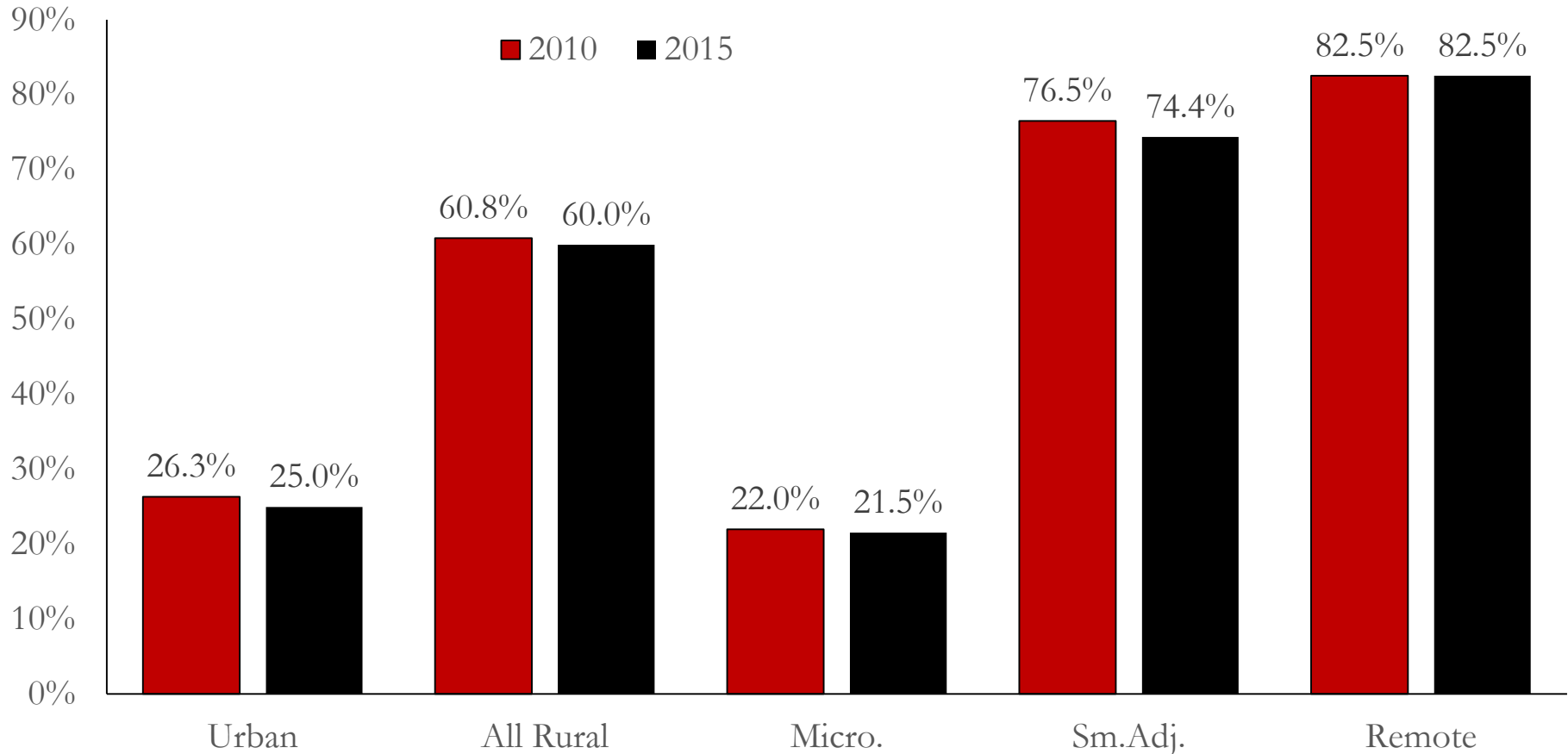
Counties without a PCP



Counties without a Pediatrician, 2010-15

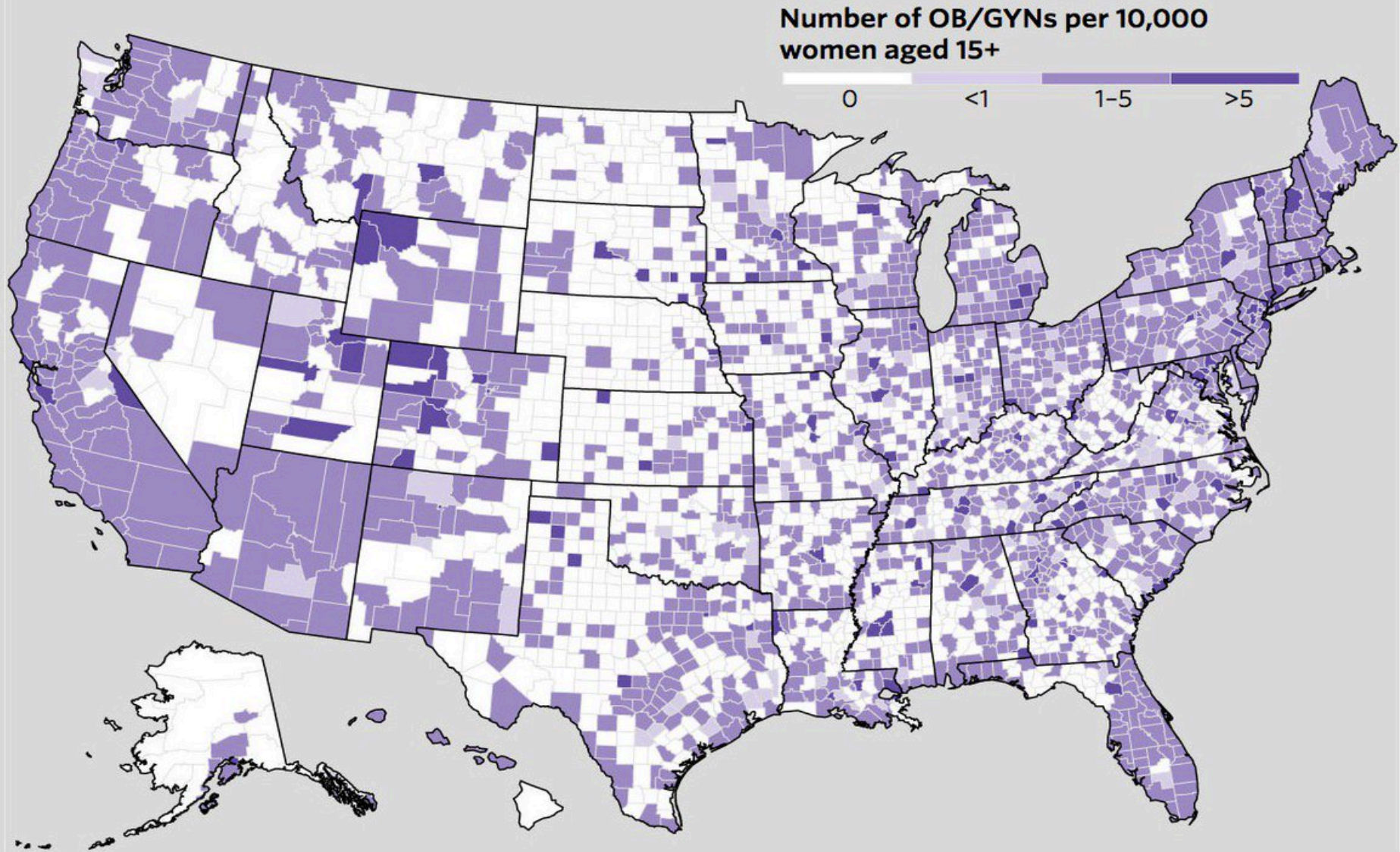


Counties without an OB/GYN, 2010-2015



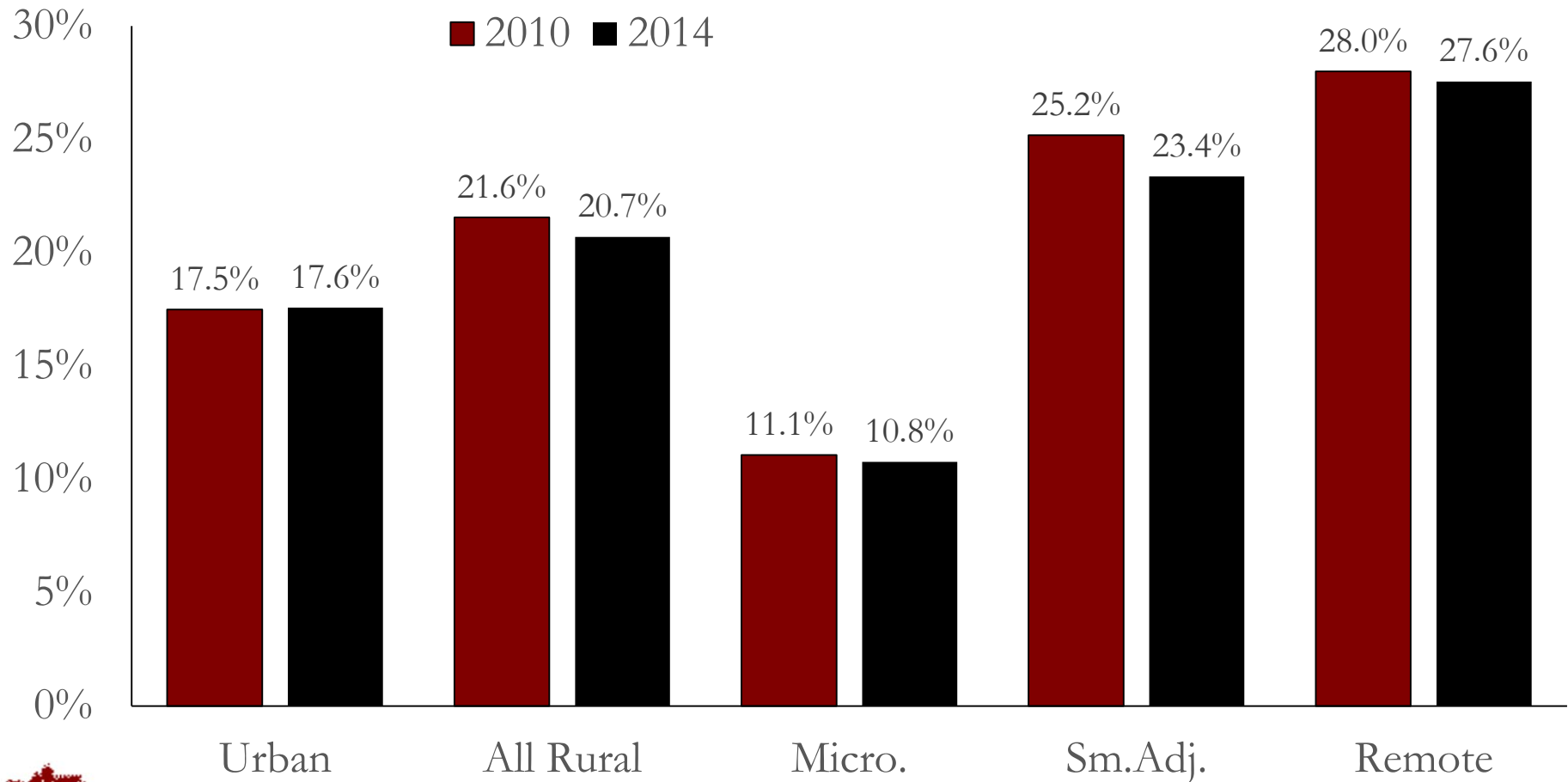
Maternity Deserts

Obstetrician/gynecologists are scarce in rural areas and small towns.

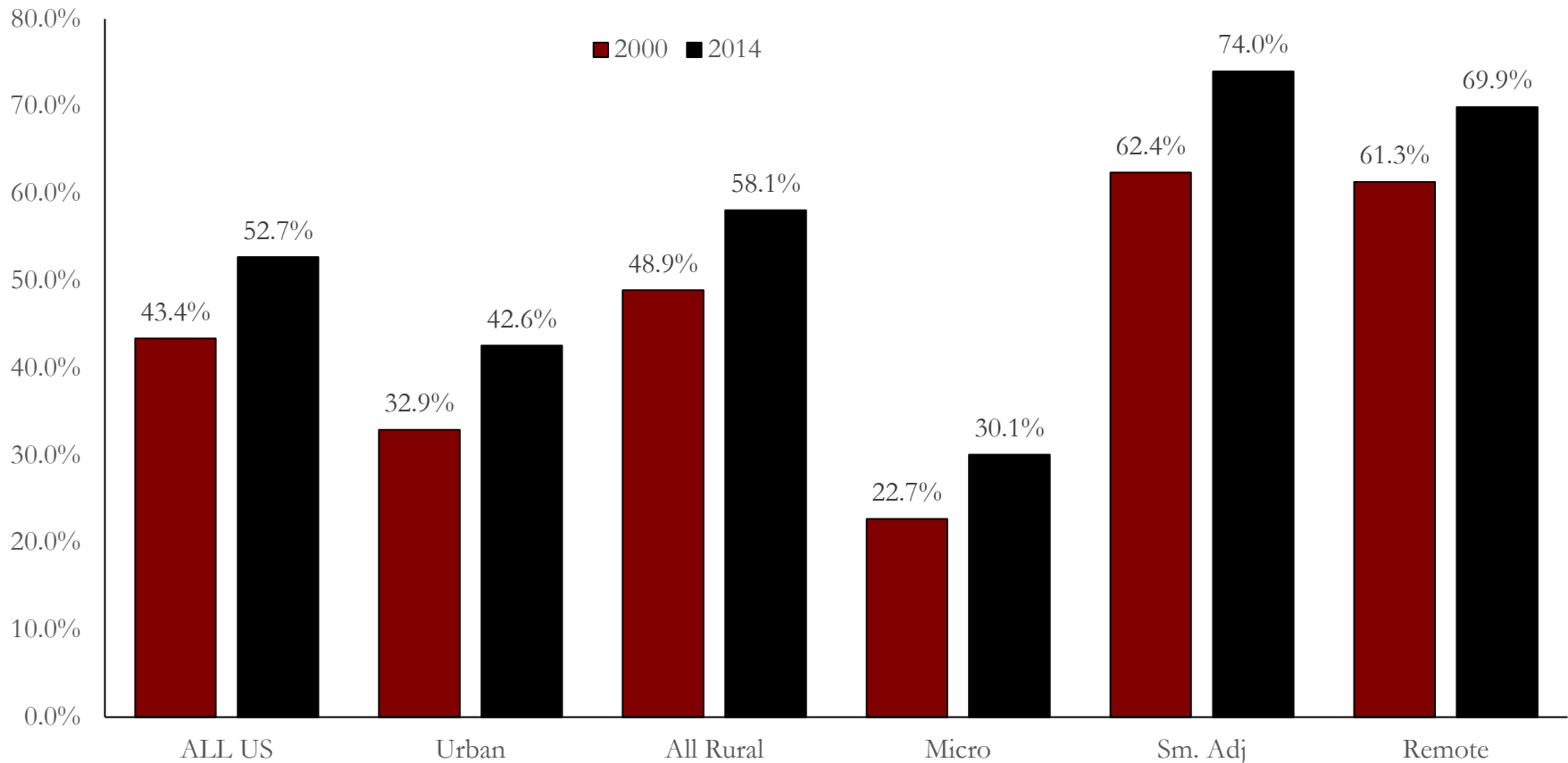


Sources: Census Bureau; Physician data derived from American Medical Association Masterfile, March 2017

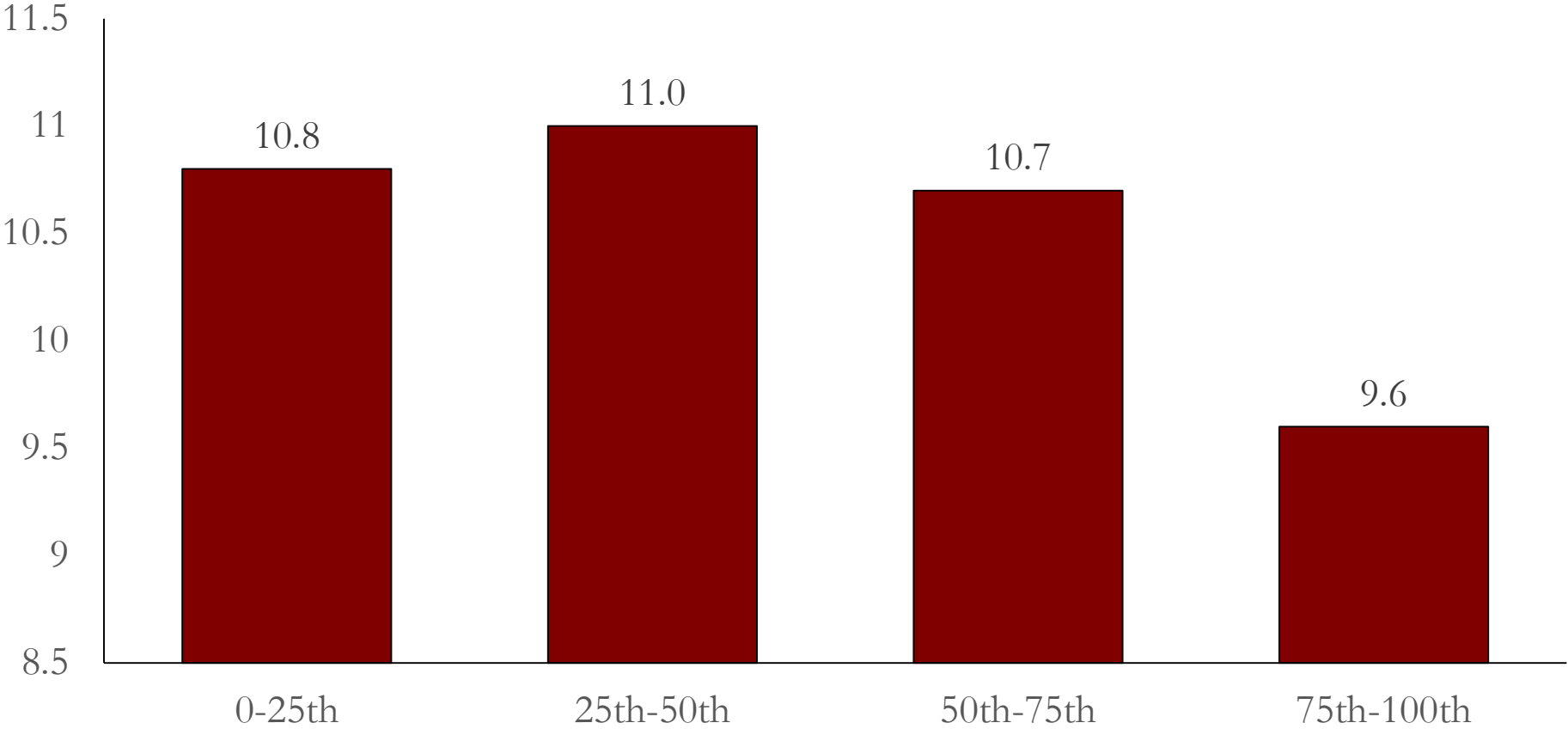
Counties without a Hospital, 2010-2014



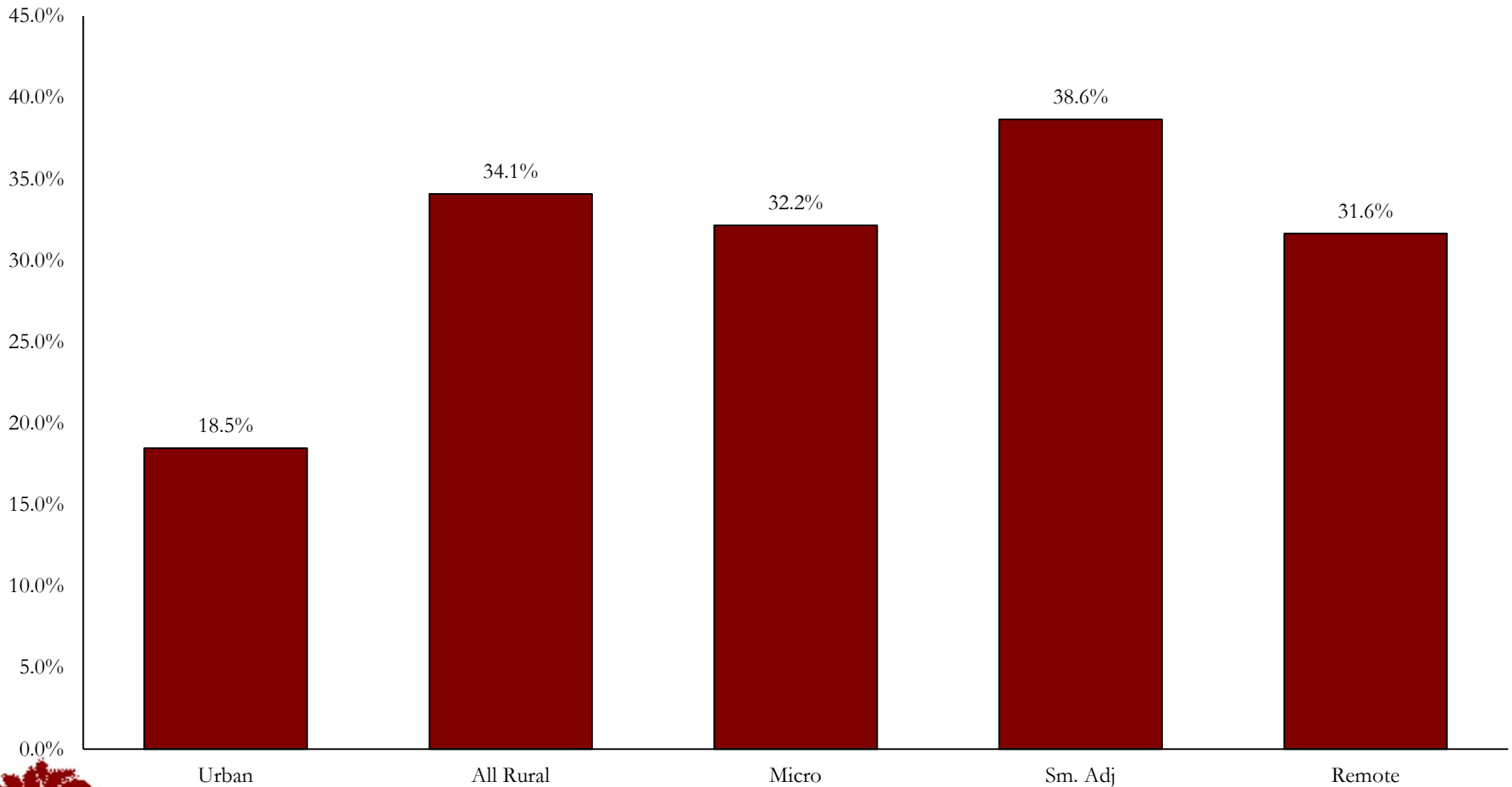
Counties without a Hospital OB unit



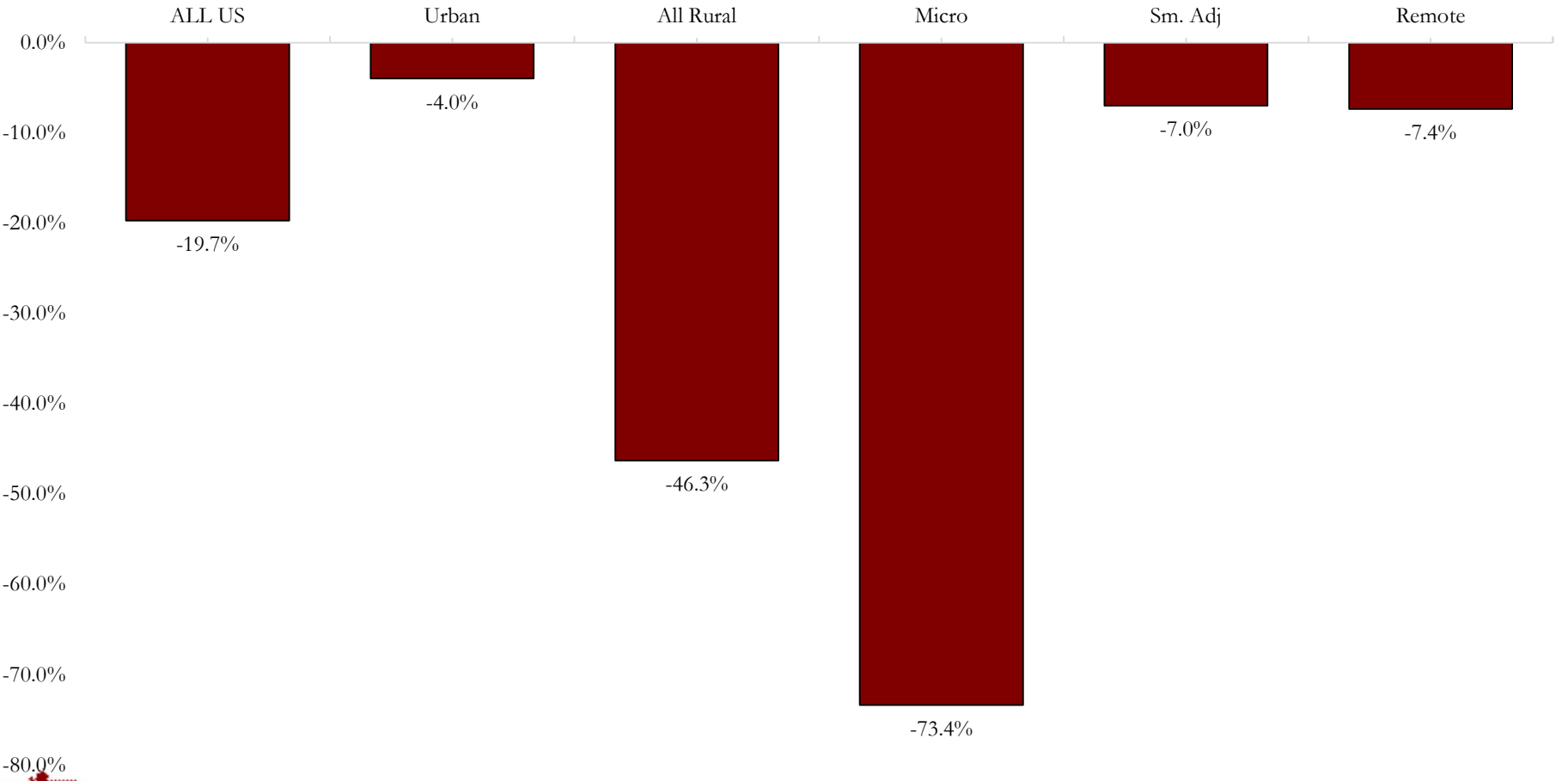
3 Year Mortality Rates & HC Index



Counties with >20% in poverty, 2013



Uninsured & ACA, 2010-2013

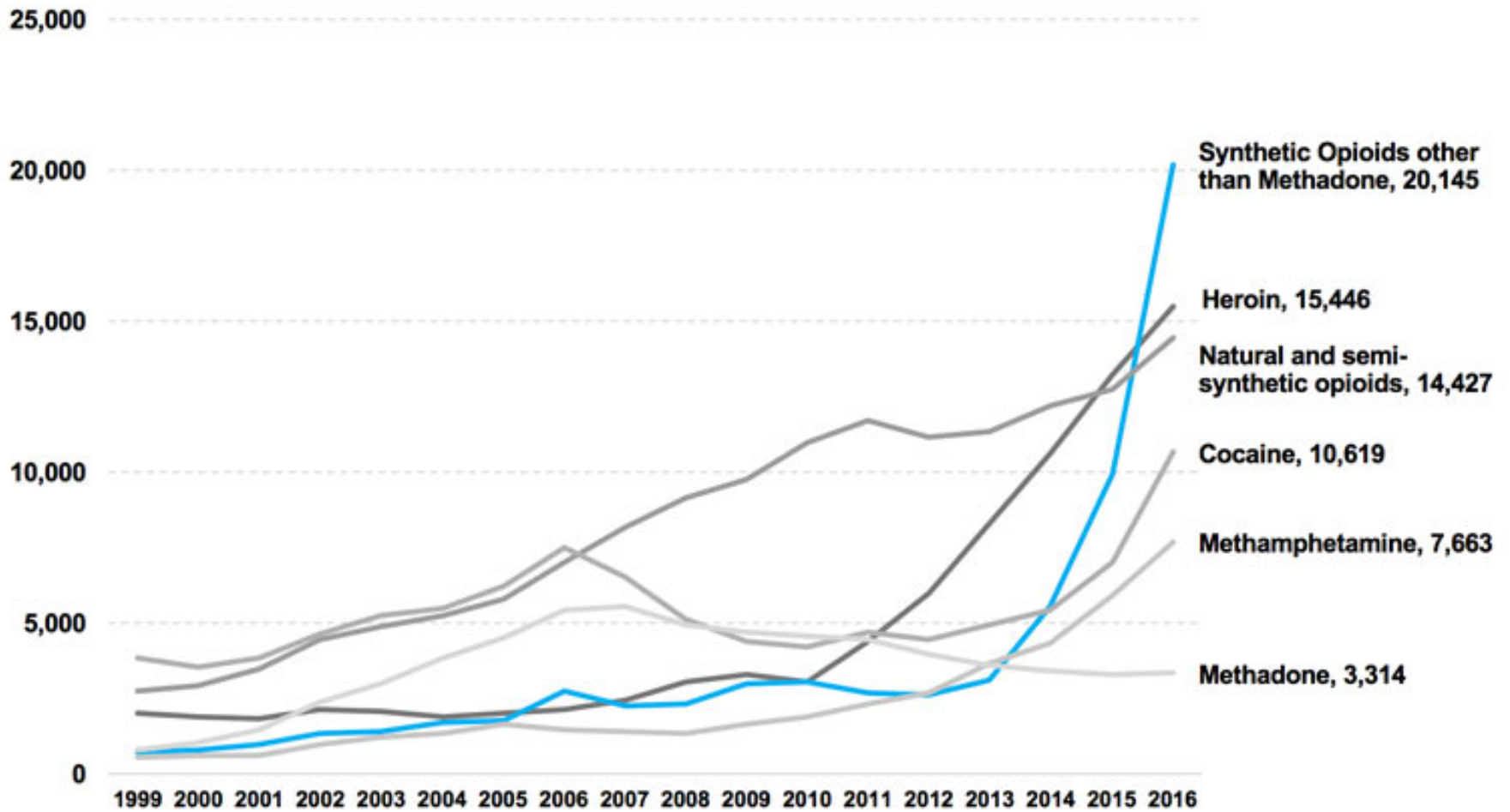


Allostatic Load, “Weathering”

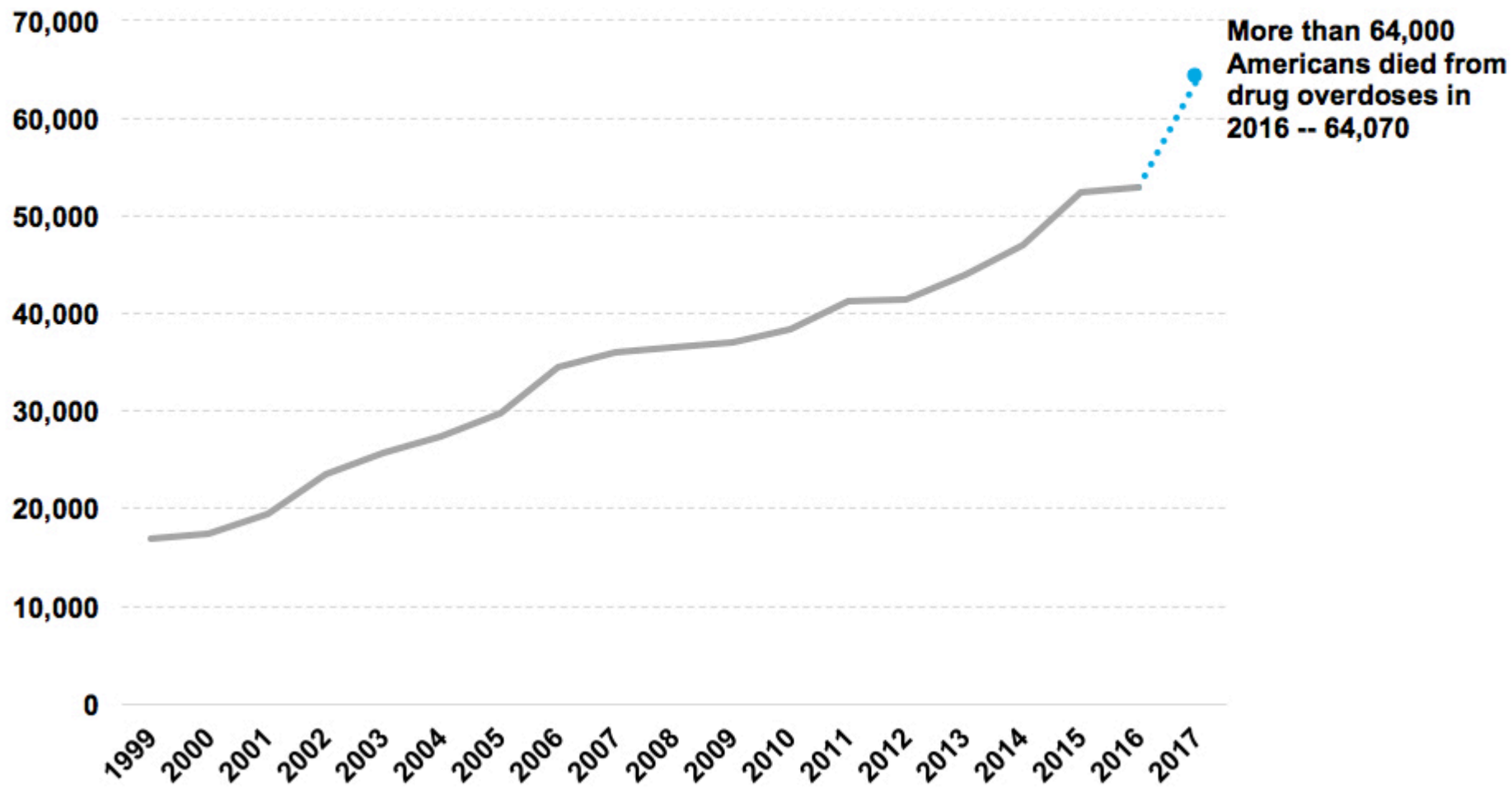
- Chronic stress leads to poor outcomes
 - ◆ Poverty, ACEs, racism, crime, environment
 - ◆ Stressors = cortisol production, chronic immune response
- Adverse Childhood Events (ACEs)
 - ◆ Abuse, neglect, other dysfunction.
 - ◆ Also associated with poor long term effects
 - ◆ Rural: more likely to have an ACE, more than one ACE
- Long term impacts
 - ◆ Stressors related to infant mortality, heart diseases, hypertension, poor mental health, premature ageing, premature mortality
- Resiliency – can mitigate adverse events, if available

OVERDOSES / OPIOIDS

Drugs Involved in U.S. Overdose Deaths, 2000 to 2016



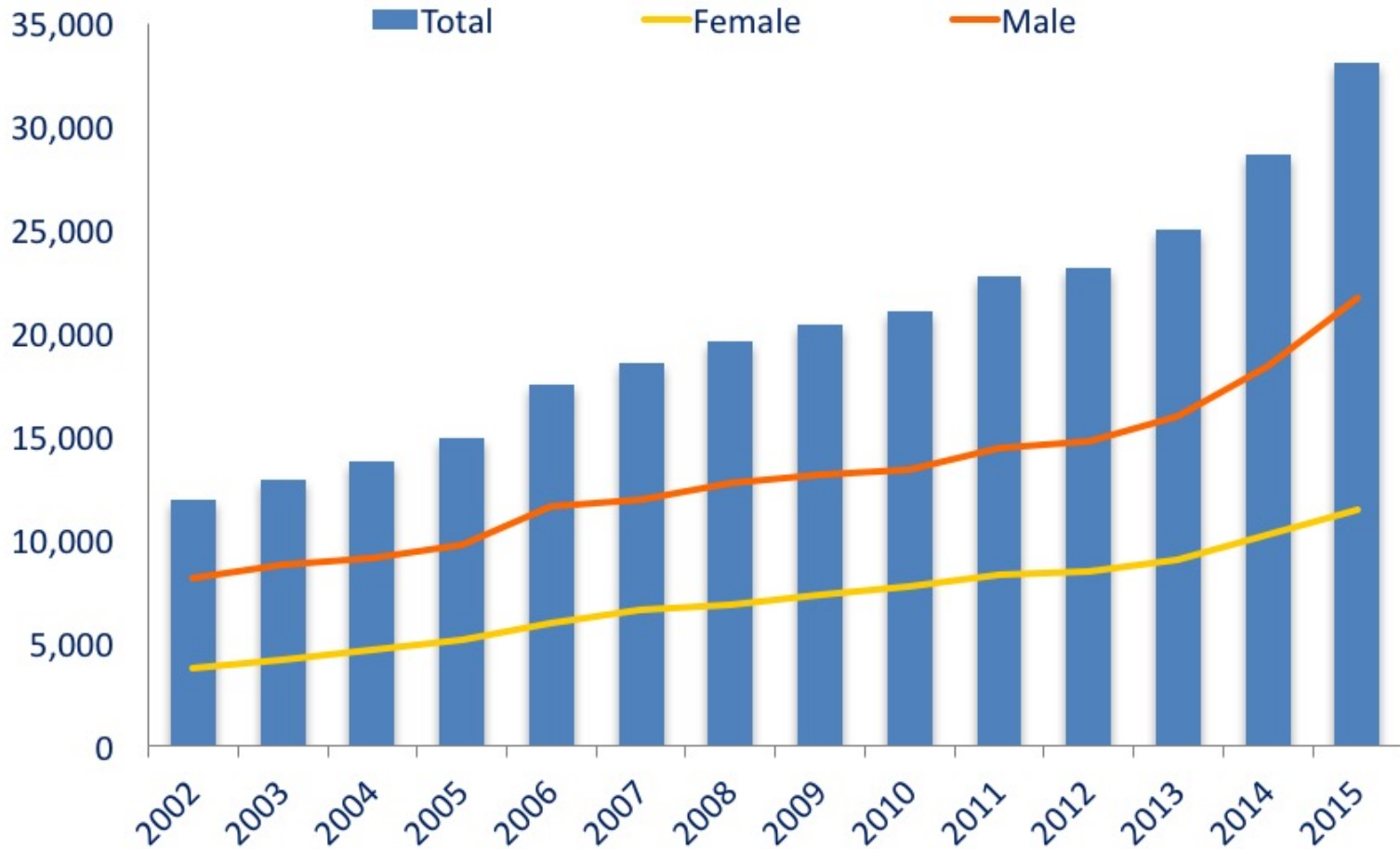
Total U.S. Drug Deaths





National Overdose Deaths

Number of Deaths Involving Opioid Drugs

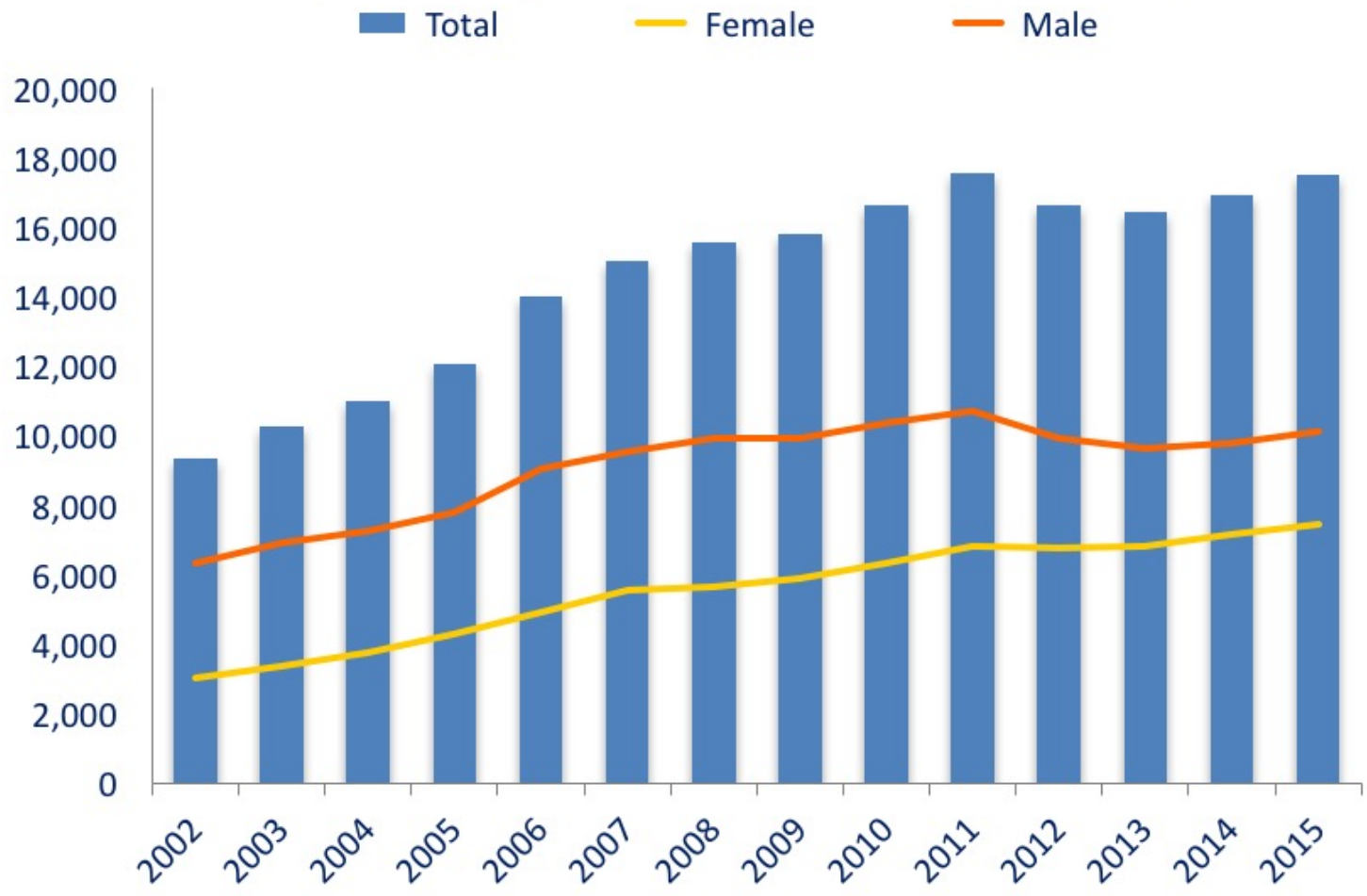


Source: National Center for Health Statistics, CDC Wonder



National Overdose Deaths

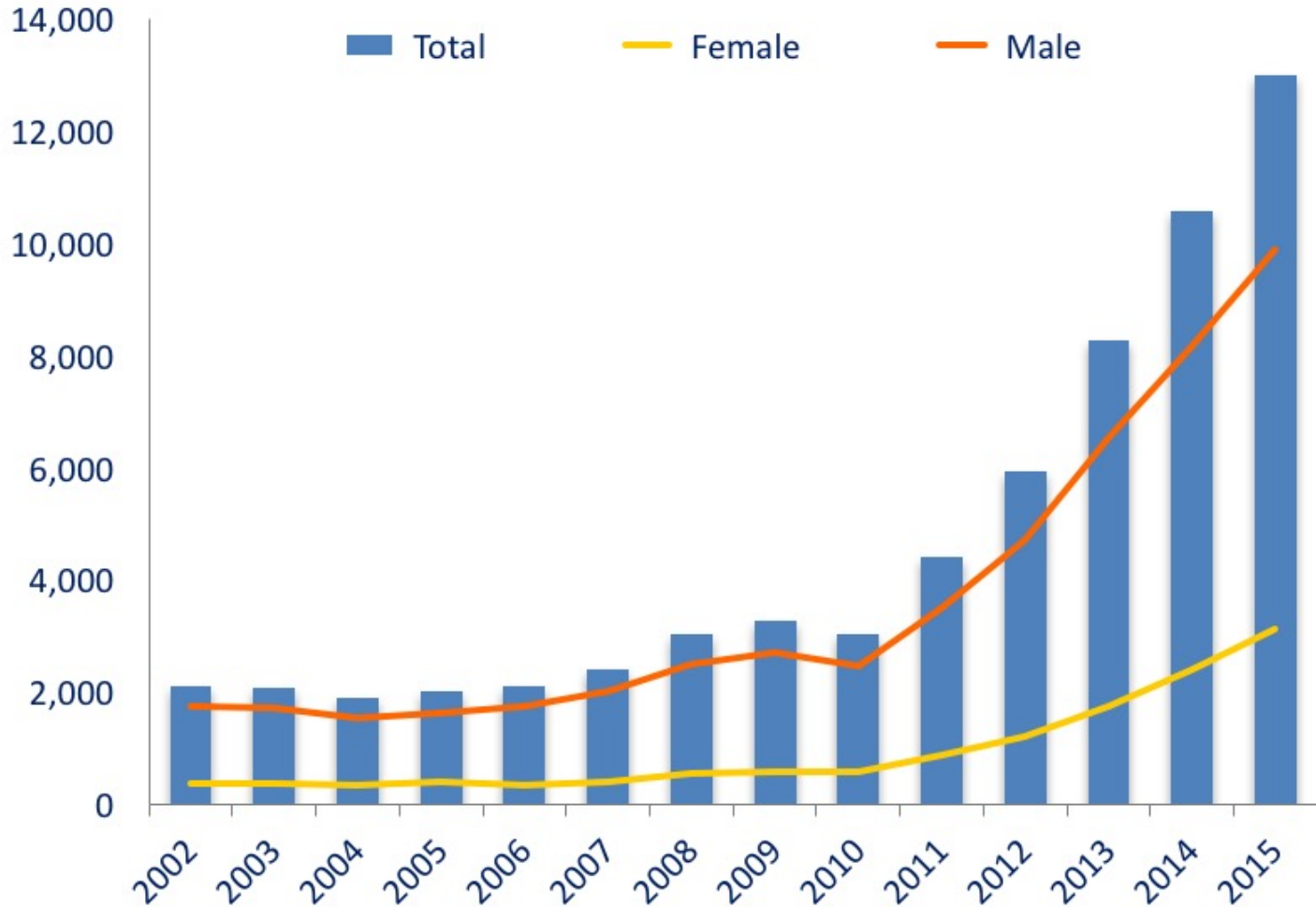
Number of Deaths Involving Prescription Opioid Pain Relievers (excluding non-methadone synthetics)



Source: National Center for Health Statistics, CDC Wonder



National Overdose Deaths Number of Deaths Involving Heroin

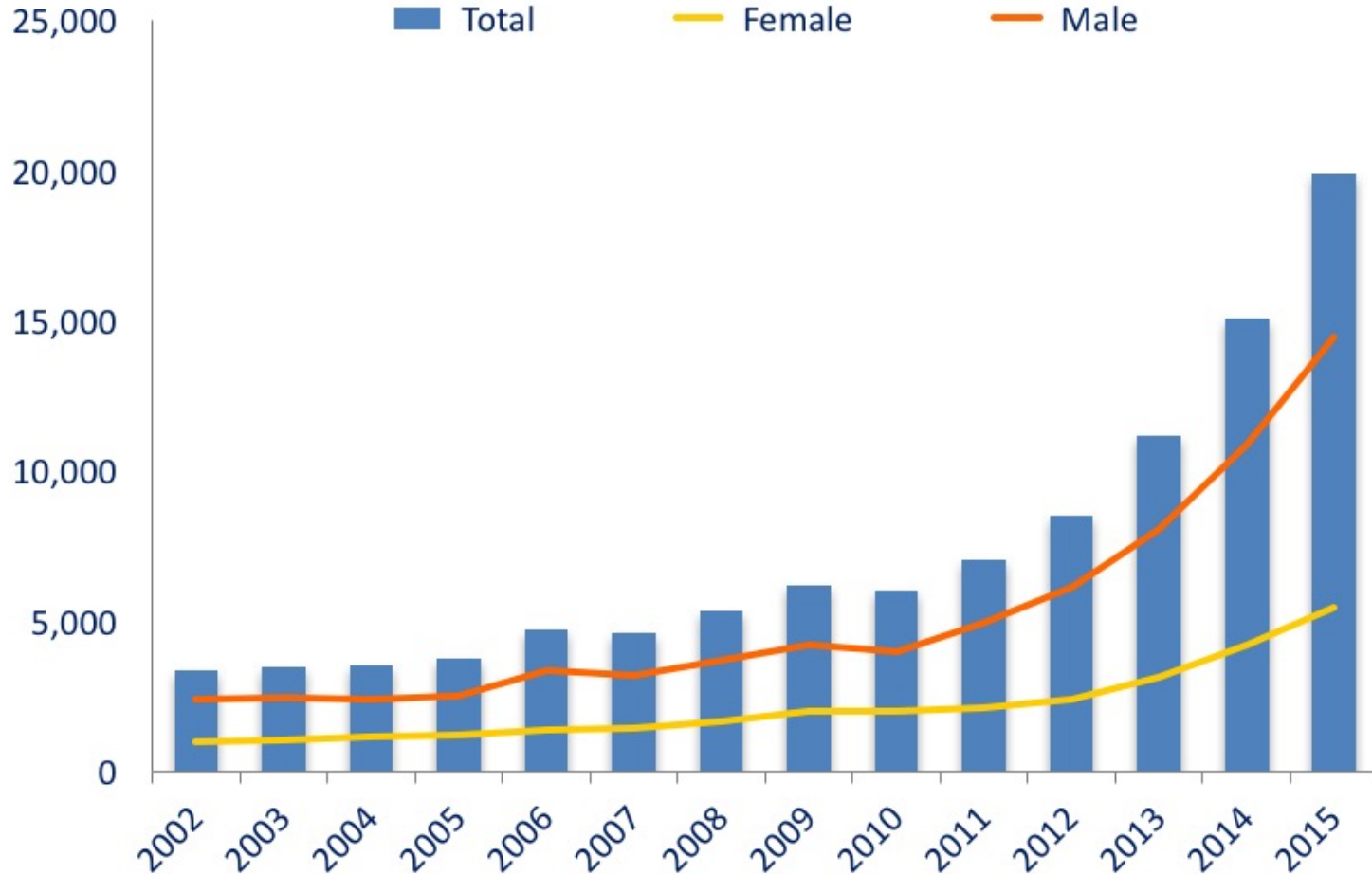


Source: National Center for Health Statistics, CDC Wonder



National Overdose Deaths

Number of Deaths Involving Heroin and Non-Methadone Synthetics (captures illicit opioids)

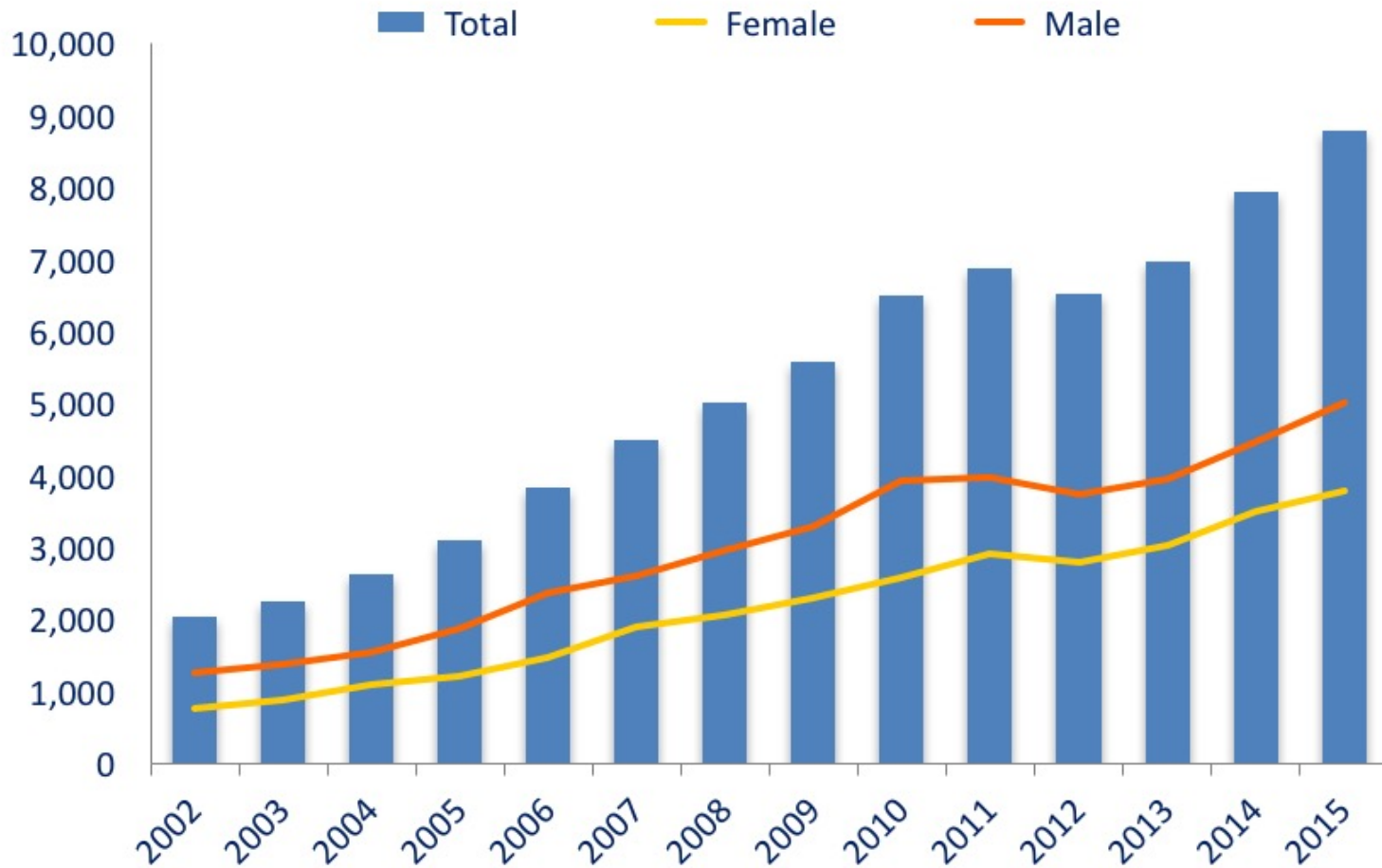


Source: National Center for Health Statistics, CDC Wonder



National Overdose Deaths

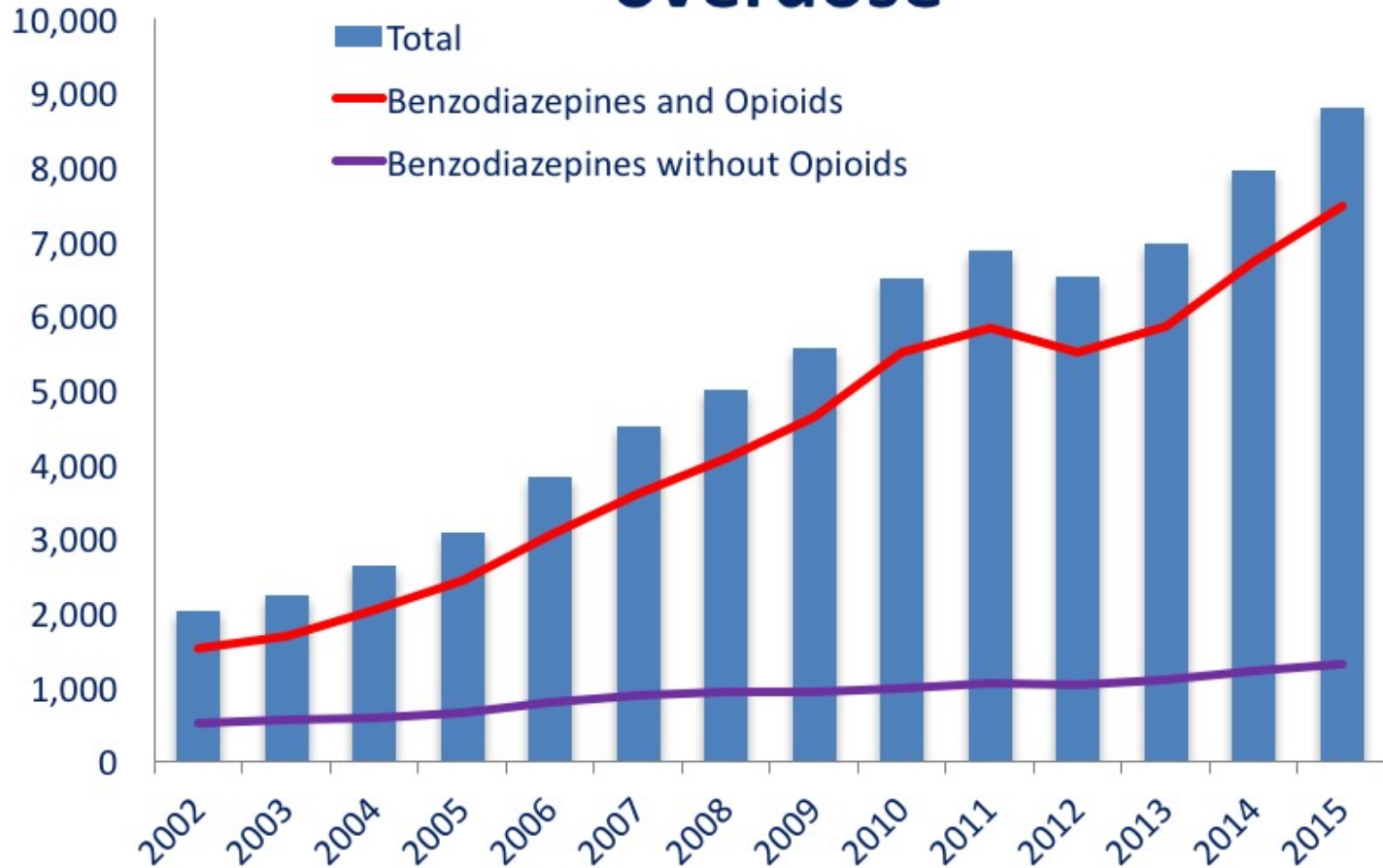
Number of Deaths Involving Benzodiazepines



Source: National Center for Health Statistics, CDC Wonder



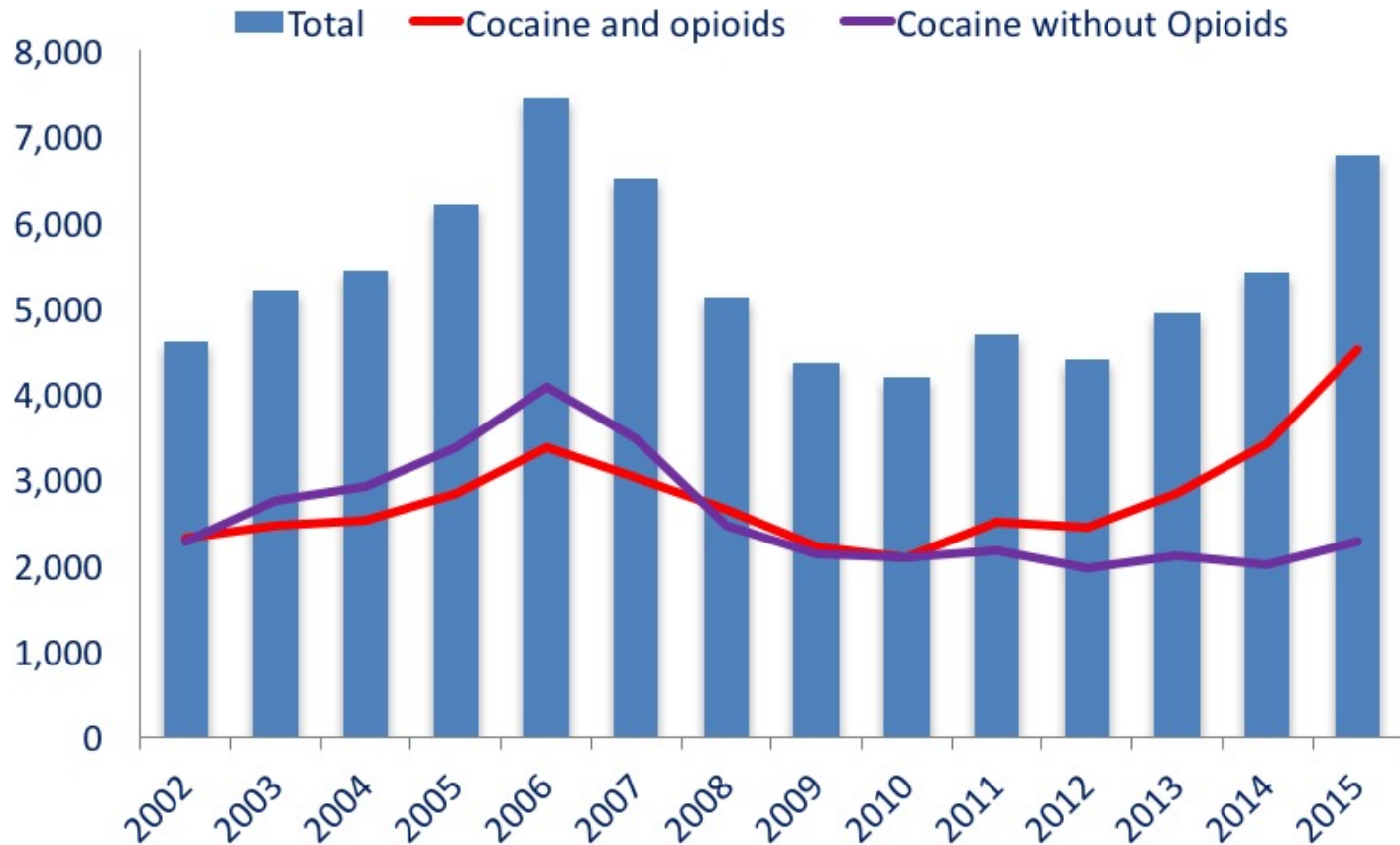
Opioid involvement in benzodiazepine overdose



Source: National Center for Health Statistics, CDC Wonder

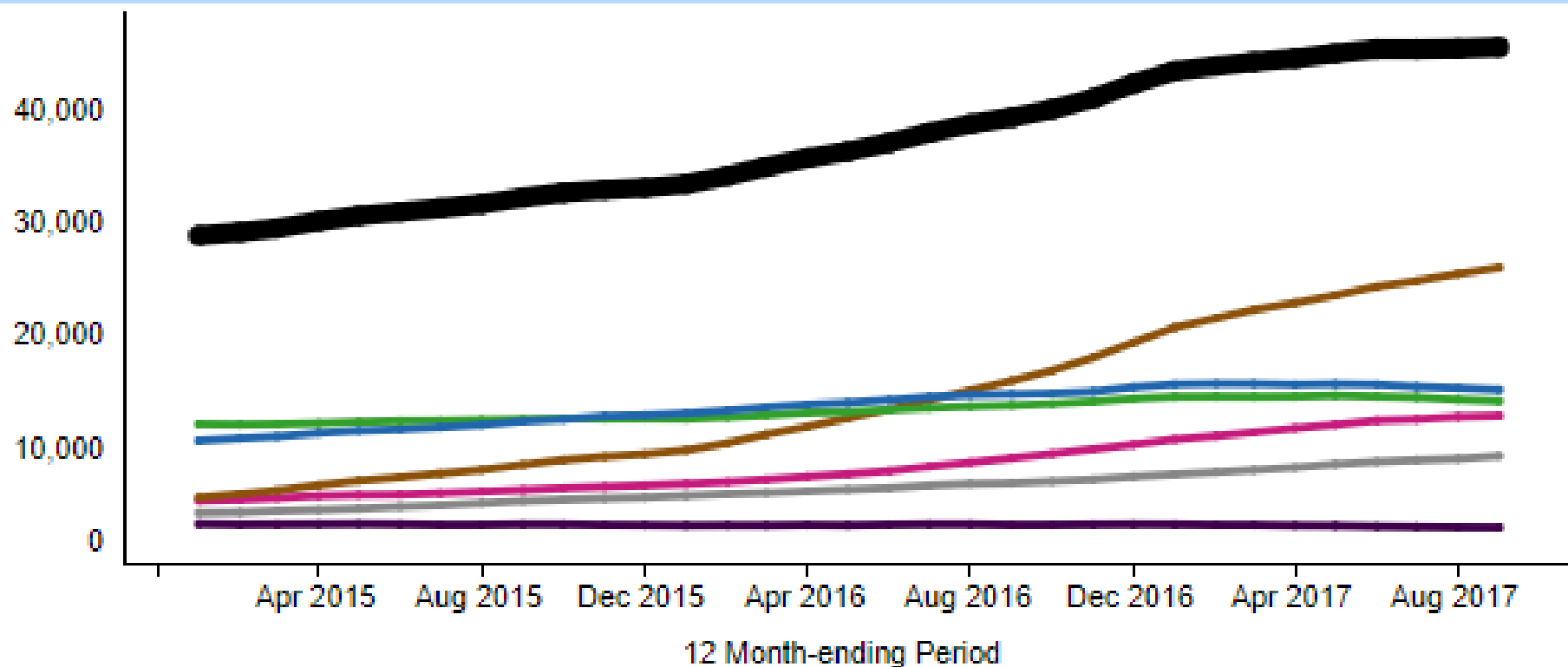


Opioid involvement in cocaine overdose



Source: National Center for Health Statistics, CDC Wonder

Figure 2. 12 Month-ending Provisional Counts of Drug Overdose Deaths by Drug or Drug Class: United States

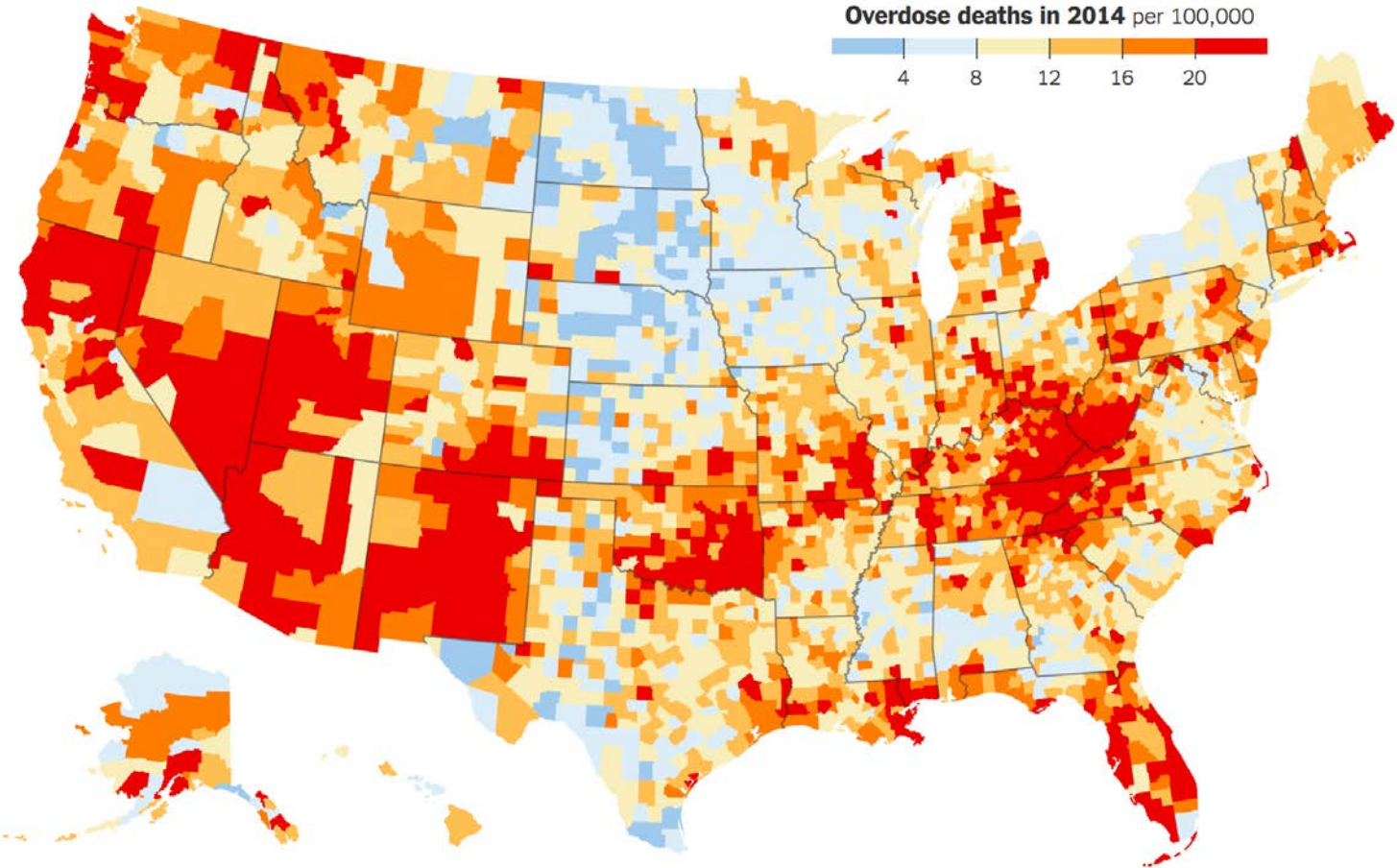


Legend for drug or drug class

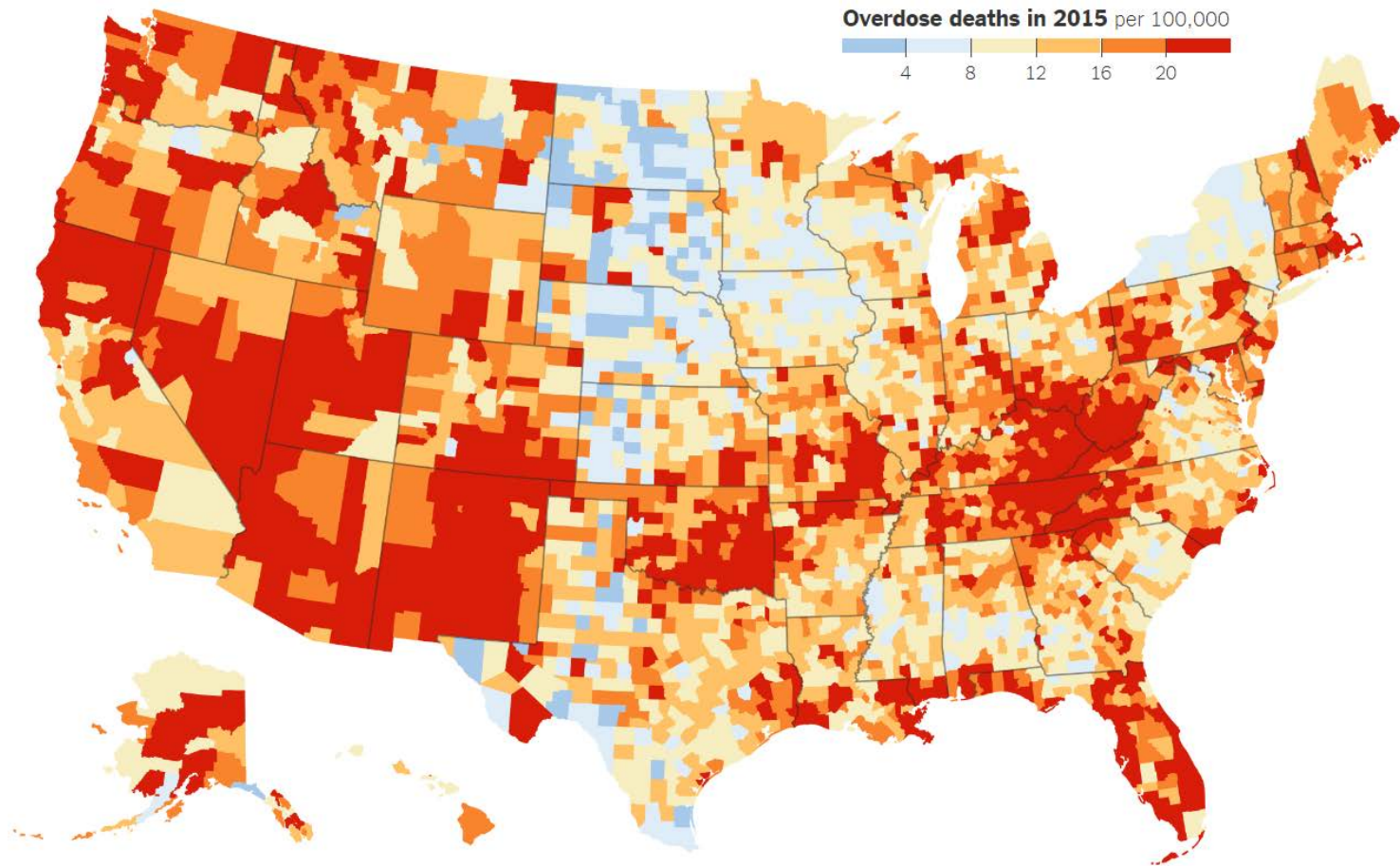
- Opioids (T40.0-T40.4, T40.6)
- Heroin (T40.1)
- Natural & semi-synthetic opioids (T40.2)
- Methadone (T40.3)
- Synthetic opioids, excl. methadone (T40.4)
- Cocaine (T40.5)
- Psychostimulants with abuse potential (T43.6)



2014: Overdose Deaths, by County



2015: Overdose Deaths, by County



Unintended Consequences?

- Naloxone availability
 - ◆ EMS, libraries, Over the counter
- Moral hazard?
 - ◆ Link with higher ED visits, thefts, Fentanyl use
 - ◆ No decrease in mortality
- As always, mixed results!
 - ◆ 9-11% reduction in deaths
- Individual effects vs. population impact

- Increased organ donation
 - ◆ 1.1% of donors in 2000
 - ◆ 13.4% in 2017

End Of Life Expenditures & Utilization

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At the Heart of Public Health Policy

End of Life Care

- End of life care is a concern for caregivers, patients, and policymakers alike
- Two pronged concern: patient preferences and costs associated with care
- Wide variations in service utilization during the last six to twelve months of life (Goodman et al, 2004; Shugarman et al, 2009).



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Variations may be due to:

- Resource Availability (distance) (Morden et al, 2012; Robinson et al, 2009)
- Hospital Type and Service Intensity (Barnato et al, 2007)
- Patient Characteristics (Shugarman et al, 2009)
 - ◆ Gender, Race, Age
- Personal Preferences (Goodman et al, 2004)



Regional variation

- Regions with higher rates of service utilization at end of life have not been found to have better outcomes or quality of care, even after adjusting for differences (Fisher et al 2003)
- Use of services has been associated with regional supply factors



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Why care about rural?

- Research concerning end of life care among rural residents is sparse
- Rural beneficiaries experience lower access to services
- 25% of hospices located in rural areas (2014)
- If they did use the service, they entered its care at a later time than urban residents (Robinson et al, 2009)
- Rural hospital closures create additional barriers for inpatient service use



Why care about inpatient hospitalizations?

- Major driver of expenditures, particularly at end of life
- Hospitalization is useful proxy for intensity of care at end of life



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Research Question

- Do rural-urban differences exist in rates of inpatient hospital admission?



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Data (Final Sample N=35,831)

- 5% sample of Medicare files (N=2,972,192)
- Files used: Beneficiary master summary, carrier claims, medpar, home health claims, hospice claims, and outpatient claims
- Restricted to FFS, Part A and Part B, covered by Medicare for at least six months prior to death
- Died between July 1- December 31, 2013
- 65 and older
- Exclusions: HMO enrollment, missing information for demographic characteristics



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Dependent Variable

- Inpatient Utilization: Yes/No in the last six months of life
- Per-beneficiary count of inpatient visits during last six months (to measure intensity)



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Independent Variable

- Whether beneficiary resided in rural/urban area, used UICs



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Control Variables (Anderson Behavior Model)

- Demographic variables: Age, Sex
- Social Structure variables: Race/ethnicity, Dual Eligibility
- Community-enabling resources: region of the country, supply side variables (number of hospital beds, SNF beds, hospice beds per 1,000 residents)
 - Ratios divided into quartiles over all counties
 - Hospital and Hospice- zero was set as the lowest quartile
- Evaluated need: chronic conditions



Analysis

- Ordinary logistic regression – examine associations of independent variables with the likelihood of at least 1 inpatient hospitalization
- Zero-inflated negative binomial regression- provides a way of modeling the excess zeros and allowing for overdispersion, examining count of hospitalizations



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Description of sample:

- Majority were female (60.2%)
- Above the age of 74 (78.7%)
- Lived in an urban location (77.7%)
- Seventy percent (70.3%) recipients of Medicare only
- Larger proportion of rural beneficiaries non-Hispanic white (90.5% versus 83.5%, $p < 0.01$)
- Rural decedents more likely to be from the South (43.1% versus 38.1%, $p < 0.01$)



Rural decedents were disproportionately:

- In counties that lacked a hospital (7.3% versus 2.6% for urban) or a hospice facility (41.3% versus 8.9%)
- In counties with the lowest quartile nationally for primary care physician/population ratios (14.9% versus 3.1% for urban)
- For those living in a county without a hospital, they also lacked access to in-county hospice



Hospitalizations in the last 6 months of life

- 65.4% of all deceased beneficiaries had at least 1 inpatient hospitalization in the 6 months before death.
- In unadjusted analysis, rural residents were no more likely than urban residents to have had at least 1 inpatient stay in the last 6 months of life.
- The visit *rate* did differ, with rural residents having slightly fewer inpatient visits, on average, than urban residents (mean: 1.25 versus 1.30; $p < 0.05$; data not in table).



Results

- Residence was not significantly associated to likelihood of any hospitalization
- No supply-side variables significantly related
- Personal characteristics:
 - ◆ Older beneficiaries were less likely to utilize inpatient services than younger beneficiaries
 - ◆ Females and racial/ethnic minorities were more likely to have inpatient visits



Results (restricted to rural)

- Consistent with total population
- Among rural residents, county-level health care resources were associated with the likelihood of hospitalization
- Beneficiaries living in counties without a hospital were less likely to have been hospitalized than those in the highest quartile for bed/population ratios (0.933, $(\exp(-0.069))$)



Discussion

- In both adjusted and unadjusted analysis, rural versus urban residence was not associated with an increased risk for hospitalization at the end of life among Medicare beneficiaries.
- Did not find a relationship with facility supply
- However, when the analysis was restricted to rural residents alone, modest effects were found for facility supply.



Discussion

- Our findings confirm prior work that found older decedents are less likely to use inpatient services, and racial/ethnic minorities are more likely to utilize inpatient services.
- Dual eligibility is a known proxy for low-income status, which we found to be negatively associated with inpatient utilization.



Limitations to our end of life studies

- One year of data
- Managed care not included
- Billing data
- Admission counts



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Conclusions

- Despite rural disadvantages...
 - Less access to health care services
 - Hospice use in rural communities is much lower
 - Home health and hospice providers face logistical issues in rural areas
 - In rural areas, informal caregiving
- No major differences between rural and urban beneficiaries in the use of inpatient services at the end of life.
- Suggests that end-of-life care is reasonably equitable for rural Medicare beneficiaries.



Questions / Comments?

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