

Dying at Home Due to Coronavirus Disease 2019

Jessie K. Edwards¹ and David Alain Wohl² 

¹Department of Epidemiology, The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA, and ²Division of Infectious Diseases, Institute of Global Health and Infectious Diseases, The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

Background. Coronavirus disease 2019 (COVID-19) is a leading cause of US deaths and when severe requires admission to a hospital; however, 9% of US COVID-19 deaths before 2022 occurred at home.

Methods. Death certificate data were used to examine the cumulative probability of dying at home from COVID-19 and from any cause in North Carolina, including by race and ethnicity.

Results. Between March 1, 2020 and December 31, 2021, 22 646 COVID-19 deaths were recorded in North Carolina; of these, 1771 (7.8%) occurred at home. Cumulative risk of dying at home with COVID-19 increased from 3.3/100 000 on December 31, 2020 to 13.0/100 000 on December 31, 2021. After standardizing each racial/ethnic group, cumulative at-home COVID-19 mortality among Hispanic people compared to White people was 9.9/100 000 versus 2.3/100 000, respectively, at year-end 2020 (difference, 7.6/100 000; 95% confidence interval [CI], 5.6–9.6) and 19.0/100 000 versus 11.4/100 000 at year-end 2021 (difference, 7.6; 95% CI, 4.9–10.4). At-home mortality among Black people was also elevated compared to White people (difference, 5.6/100 000; 95% CI, 3.7–7.4) at year-end 2021. Rates of dying at home from any cause increased overall but were greatest among Hispanic people.

Conclusions. By the end of 2021, the risk of dying at home from COVID-19 increased, especially for persons of color. The risk of dying at-home from any cause also increased for all but more so for Hispanic persons. These findings suggest perennial barriers to care prevent those with progressive COVID-19 from accessing medical attention and the need for initiatives that extend healthcare access for those disproportionately impacted by COVID-19 to prevent avoidable death.

Keywords. COVID-19; mortality; at-home; disparities.

Coronavirus disease 2019 (COVID-19) has become a leading cause of death and reduced life expectancy in the United States, especially among Black and Latino populations [1]. The progression of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection from symptom onset to severe life-threatening pneumonia occurs over the course of several days, allowing those with COVID-19 to seek medical care as their condition worsens. Hospitalization may be required when supplemental oxygen, ventilatory support, or parenteral therapeutics are necessary. However, of the 848 886 deaths involving COVID-19 recorded in the United States in 2020 and 2021, 72% occurred in the hospital or emergency room; another 18% of these deaths were patients in nursing or long-term care facilities and 8%, more than 70 000 individuals, died with COVID-19 at home [2].

As efforts to manage acute progressive COVID-19 to prevent death are best made in a hospital setting where intensive care can be provided, at-home COVID-19 mortality can serve as evidence of obstacles to urgently needed care and potentially life-saving interventions. During the pandemic, health-seeking behaviors and healthcare services have been substantially altered leading to reductions in healthcare services utilization. Fear of infection led many to avoid medical facilities, and the capacity of clinics, urgent care centers, and emergency departments were reduced especially during surges in COVID-19 cases due to infection control measures and staffing shortages [3, 4]. These pandemic-related bottlenecks are likely to exacerbate perennial barriers to healthcare in the United States including lack of health insurance and transportation that disproportionately affect people of color, those with fewer financial resources, and the undocumented—populations who are also disproportionately at risk for SARS-CoV-2 infection [5].

We examined the cumulative probability of dying at home due to COVID-19 among persons in North Carolina over the course of the pandemic and the differences in this risk by demographic characteristics, including race and ethnicity. We also examined the excess risk of dying at home due to any cause during the pandemic compared to expected at-home mortality based on data from 2014 to 2019 to place COVID-19 at-home deaths into context.

Received 20 July 2022; editorial decision 22 August 2022; accepted 23 August 2022; published online 25 August 2022

Correspondence: David Alain Wohl, MD, Professor of Medicine, Institute of Global Health and Infectious Diseases, The University of North Carolina at Chapel Hill, 130 Mason Farm Road, Campus Box 7215, Chapel Hill, NC 27599 (wohl@med.unc.edu).

Open Forum Infectious Diseases®

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<https://doi.org/10.1093/ofid/ofac439>

METHODS

Data Sources

Data on deaths in North Carolina from January 1, 2014 to December 31, 2021 were obtained from death certificate data managed by the North Carolina Department of Health and Human Services (NCDHHS) State Center for Health Statistics. We aggregated the number of deaths for each day for strata defined by age, sex, race/ethnicity (non-Hispanic White, non-Hispanic Black, non-Hispanic American Indian, non-Hispanic Asian/Pacific Islander, or Hispanic), county of residence, cause of death (COVID-19 or non-COVID-19), and place of death (at home or elsewhere). We merged the mortality data with census data provided by the National Center for Health Statistics, describing the estimated population size by age, sex, and race/ethnicity for all North Carolina counties over the relevant time period.

To describe those dying at home due to COVID-19 and the COVID-19-related mortality risk by population characteristics, we focused on the time period from March 1, 2020 to December 31, 2021. We defined a death to be COVID-19-related if COVID-19 *International Classification of Disease* (ICD)-10 code U07.1 was listed as either an underlying or contributing cause of death. If the cause of death was unknown ($n = 664$, or $<1\%$), we assumed that the death was not related to COVID-19. The “place of death” designation on the death certificates was used to determine whether a decedent died at home (“decedents home”) rather than somewhere else (inpatient facility, emergency room/outpatient facility, dead on arrival, hospice facility, long-term care/nursing home, or other). We assumed that decedents with unknown place of death ($n = 168$ total deaths, 11 COVID-19 deaths) did not die at home.

Data Analysis

We first described the demographic characteristics of people dying due to COVID-19 at home. Specifically, we present the number and proportion of at-home COVID-19 deaths occurring in each age category, by sex, by race/ethnicity, by education, and by place of residence (within vs outside the city limits). For context, we also present the distribution of these characteristics among all COVID-19 deaths.

Next, we present the cumulative number of North Carolinians dying at home from COVID-19 per 100 000 residents stratified by race and ethnicity over the period from March 1, 2020 to December 31, 2021. Cumulative at-home COVID-19 mortality was defined as the cumulative number of deaths related to COVID-19 occurring at home on or before each day divided by the population in relevant groups of interest and multiplied by 100 000 for ease of interpretation. For context, we also present cumulative COVID-19 mortality, regardless of place of death, by race and ethnicity. Cumulative mortality is not presented for non-Hispanic American Indian/Alaska Natives due to small cell sizes.

In addition to presenting crude cumulative at-home COVID-19 mortality by race and ethnicity, we present age-adjusted estimates that account for differences in population age structure by race and ethnicity. Age adjustment was performed via standardization using stabilized inverse probability weights. Specifically, using the North Carolina population data, we fit a multinomial logistic regression model to estimate the probability of being a member of each race/ethnic group both overall and by age. Weights were the overall probability of being in each group divided by the probability of being in that group conditional on age. Standardized cumulative at home COVID-19 mortality was estimated by accumulating the weighted number of deaths over time for each racial/ethnic group and dividing by the relevant group’s population. Cumulative at-home COVID-19 mortality was also summarized over the period described above by county.

Finally, to examine whether the pandemic was driving at-home mortality due to causes beyond COVID-19, we compared the monthly probability of dying at home due to any cause in the period from March 1, 2020 to July 31, 2021 to the average monthly probability of dying at home from 2014 to 2019 (death certificate data from North Carolina were available only up to July 31, 2021). These monthly probabilities were computed by summing deaths at home from any cause in each month and dividing by the estimated population of North Carolina in that year as reported by the National Center for Health Statistics. We also compare excess at-home mortality (defined as the difference between the monthly probability of dying at home during the pandemic period and the expected probability for that month based on data from 2014 to 2019) by race and ethnicity. Expected mortality in each month of the pandemic was estimated using predictions from a logistic regression model for the number of at-home deaths divided by population fit to each stratum of age and race in each month from January 2014 to December 2019. The model included indicator variables for month of the year to account for seasonality and a linear term for year to capture calendar-time trends in at-home mortality.

Consent Statement

The study was reviewed by the Office of Human Research Ethics at the University of North Carolina, which determined that the submission does not constitute human subjects research as defined under federal regulations [45 CFR 46.102 (e or l) and 21 CFR 56.102(c)(e)(l)] and, therefore, does not require approval from this institutional review board.

RESULTS

Age, Race, and Ethnicity and At-Home Coronavirus Disease 2019 Mortality Risk

Between March 1, 2020 and December 31, 2021, there were 22 646 deaths due to COVID-19 recorded in North Carolina; of

these, 1771 (7.8%) occurred at home (Table 1). People dying at home due to COVID-19 were on average younger and less likely to live inside city limits than the overall population of people dying due to COVID-19. Like COVID-19 deaths in general, most COVID-19 deaths at home were among those older than 70 years of age. However, 42% of at-home COVID-19 deaths occurred among those under 70 years of age compared to 36% of all COVID-19 deaths. At-home COVID-19 mortality risk was heterogeneous by race and ethnicity (Table 1).

By December 31, 2020, 454 people in North Carolina had died at home due to COVID-19, for a cumulative risk of 4.3 per 100 000. By December 31, 2021, 1771 had died at home due to COVID-19, for a cumulative risk of 16.9 per 100 000 (Table 2). Trends in at-home COVID-19 mortality differed by race and ethnicity. At the end of 2020, compared to non-Hispanic White people, at-home COVID-19 mortality was elevated for Hispanic people and for non-Hispanic Black people. However, by the end of 2021, cumulative at-home

COVID-19 mortality was lower among Hispanic people than among non-Hispanic White individuals but remained elevated among non-Hispanic Black individuals compared to non-Hispanic White people (Figure 1A, Table 2).

After standardizing each racial/ethnic group to the North Carolina population age distribution, disparities in at-home COVID-19 mortality were accentuated (Table 2). Standardized cumulative at-home COVID-19 mortality was highly elevated among Hispanic people compared to White people at both timepoints: by December 31, 2020, standardized mortality was 9.9 per 100 000 among Hispanic people compared to 2.3 per 100 000 among White people (difference, 7.6 per 100 000; 95% confidence interval [CI], 5.6–9.6) and, by December 31, 2021, standardized mortality was 19.0 per 100 000 among Hispanic people compared to 11.4 per 100 000 among White people (difference, 7.6; 95% CI, 4.9–10.4). By December 31, 2021, standardized mortality was also highly elevated among Black people (16.9 per 100 000) compared to White people (difference, 5.6 per 100 000; 95% CI, 3.7–7.4).

Patterns in racial/ethnic disparities in cumulative at-home COVID-19 mortality generally reflect patterns in overall cumulative COVID-19 mortality for non-Hispanic Black and non-Hispanic Asian groups (Figure 1B). However, cumulative at-home COVID-19 mortality for Hispanic people was elevated over that among non-Hispanic White people to a greater extent than observed for overall cumulative COVID-19 mortality. Moreover, Hispanic people had the highest age-standardized cumulative at-home COVID-19 mortality, whereas Black people had the highest age-standardized overall COVID-19 mortality.

Age, Race/Ethnicity, and At-Home All-Cause Mortality Risk

Between 2014 and 2019, all-cause at-home deaths increased by 2%–6% annually, but, in 2020, the non-COVID-19 at-home death rate increased by 23% compared to 2019, peaking along with the COVID-19 at-home death rate during the end of the year and into 2021 (Figure 2).

From 2014 to 2020, before the COVID-19 pandemic, the median age of those dying at home from any cause in North Carolina was 77 years, and during the pandemic (March 1, 2020 through December 31, 2021) it declined to 74 years. For the year preceding the pandemic (March 1, 2019 through February 28, 2020), the average rate of at-home deaths per month was 28.8 per 100 000 for non-Hispanic White people, 17.5 per 100 000 for non-Hispanic non-White people, and 3.6 per 100 000 for Hispanic people. During the first year of the pandemic (March 1, 2020 to February 28, 2021), the average rate of at-home death per 100 000 per month rose 30% for non-Hispanic white people (37.3 at home deaths per 100 000), 40% for non-Hispanic non-White people (24.5 at-home deaths per 100 000), and 65% for Hispanic people (5.9 at-home deaths per 100 000) (Supplemental Figures 1 and 2).

Table 1. Characteristics of 22 646 People in North Carolina Dying Due to COVID-19 and 1771 People in North Carolina Dying at Home Due to COVID-19 Between March 1, 2020 and December 31, 2021

Characteristic	All COVID-19 Deaths (N = 22 646)		COVID-19 Deaths at Home (N = 1771)	
	N	%	N	%
Age				
<18	17	0.1	3	0.2
18–34	303	1.3	45	2.5
35–54	2195	9.7	253	14.3
55–69	5709	25.2	439	24.8
70–84	8939	39.5	571	32.2
85+	5483	24.2	460	26.0
Race				
NH White	15 520	68.5	1180	66.6
NH Black	5396	23.8	426	24.1
NH American Indian/Alaska Native	314	1.4	11	0.6
NH Asian	361	1.6	33	1.9
Hispanic	1055	4.7	121	6.8
Sex				
Male	10 651	47.0	777	43.9
Female	11 995	53.0	994	56.1
Education				
<HS	5782	25.5	462	26.1
Graduated HS or some college	11 718	51.7	892	50.4
Associate Degree	2033	9.0	169	9.5
Bachelor's Degree	2002	8.8	157	8.9
Postgraduate Degree	973	4.3	82	4.6
Unknown	138	0.6	9	0.5
Residence				
Outside city limits	10 853	47.9	910	51.4
Inside city limits	11 651	51.4	838	47.3
Unknown	142	0.6	23	1.3

Abbreviations: COVID-19, coronavirus disease 2019; HS, high school; NH, non-Hispanic.

Table 2. Cumulative At-Home COVID-19 Mortality in North Carolina by Race and Ethnicity on December 21, 2020 and December 31, 2021: Crude and Age-Standardized Results

Date	Race/Ethnicity	Cumulative at-Home Mortality per 100 000	Mortality Difference (Crude)	95% CI	Mortality Ratio	95% CI
December 31, 2020	Overall	4.3				
December 31, 2021		16.9				
December 31, 2020	NH White	2.7	0		1	
	NH Black	4.3	1.6	0.7–2.5	1.6	1.25–2.04
	NH Asian	3.2	0.5	–1.5 to 2.4	1.17	0.64–2.15
	Hispanic	5.0	2.3	0.9–3.7	1.84	1.35–2.51
December 31, 2021	NH White	13.1	0		1	
	NH Black	14.9	1.8	0–3.6	1.14	1.01–1.29
	NH Asian	7.7	–5.3	–8.4––2.3	0.59	0.4–0.87
	Hispanic	10.4	–2.6	–4.8––0.5	0.80	0.65–0.98
<u>Age Standardized</u>						
December 31, 2020	NH White	2.3	0		1	
	NH Black	4.9	2.6	1.6–3.6	2.12	1.66–2.7
	NH Asian	3.8	1.5	–0.6 to 3.6	1.64	0.94–2.87
	Hispanic	9.9	7.6	5.6–9.6	4.27	3.32–5.48
December 31, 2021	NH White	11.4	0		1	
	NH Black	16.9	5.6	3.7–7.4	1.49	1.32–1.68
	NH Asian	9.4	–1.9	–5.3 to 1.4	0.83	0.59–1.18
	Hispanic	19.0	7.6	4.9–10.4	1.67	1.43–1.95

Abbreviations: CI, confidence interval; COVID-19, coronavirus disease 2019; NH, non-Hispanic.

DISCUSSION

Dying at home with COVID-19 rather than in a medical facility where lifesaving interventions are available signals the existence of barriers to urgently needed healthcare. We found that in North Carolina, 1 of every 15 COVID-19 deaths has occurred at home and the risk of dying at home with COVID-19 was greater among Hispanic and non-Hispanic Black people compared to non-Hispanic White people. After adjustment for age, the risk of at-home COVID-19 death for both Hispanic and non-Hispanic Black individuals was at least double that of non-Hispanic Whites.

Although in North Carolina, as in the United States as a whole, non-Hispanic Black and Hispanic people have experienced higher rates of confirmed COVID-19 compared to non-Hispanic White people, contributing to an elevated risk of dying from COVID-19, we found that the increased risk of dying at home with COVID-19 among Hispanics was in excess of the higher COVID-19 mortality rate experienced by this population. By mid-2021, the risk of dying at home with COVID-19 among Hispanic North Carolinians surpassed that of non-Hispanic Blacks, who had higher rates of COVID-19 mortality at that time.

We examined potential explanations for the heightened risk of at-home COVID-19 deaths among persons of color within the data that was available from death certificates including

educational attainment and residence in an urban versus non-urban area. Education level among those dying of COVID-19 at home was similar to all who died from COVID-19 in North Carolina. Likewise, although rates of at-home COVID-19 death were greatest in the counties with the highest COVID-19 mortality, those dying of COVID-19 at home were more likely to reside in rural areas, where needed healthcare is generally less readily accessible compared to urban centers.

Our finding that at-home mortality from any cause rose dramatically during the pandemic suggests that COVID-19 impeded access to care broadly. The pandemic-forced restrictions on face-to-face clinic encounters limited access to routine and urgent care [3]. Furthermore, during surges in COVID-19, many urgent and emergency care centers became crowded leading to longer than usual wait times [4]. Finally, many ill persons delayed or avoided medical care due to concern for exposure to the virus.

Although these COVID-19-related barriers to care may have led to delays in health-seeking, the disproportionate risk to persons of color indicates that other more pervasive forces were also operative. Reduced access to primary and urgent care due to COVID-19 infection control measures and thinly stretched urgent care services are likely to have the greatest impact on those whose access to such care is already challenged. The disproportionate toll of COVID-19 among Hispanics

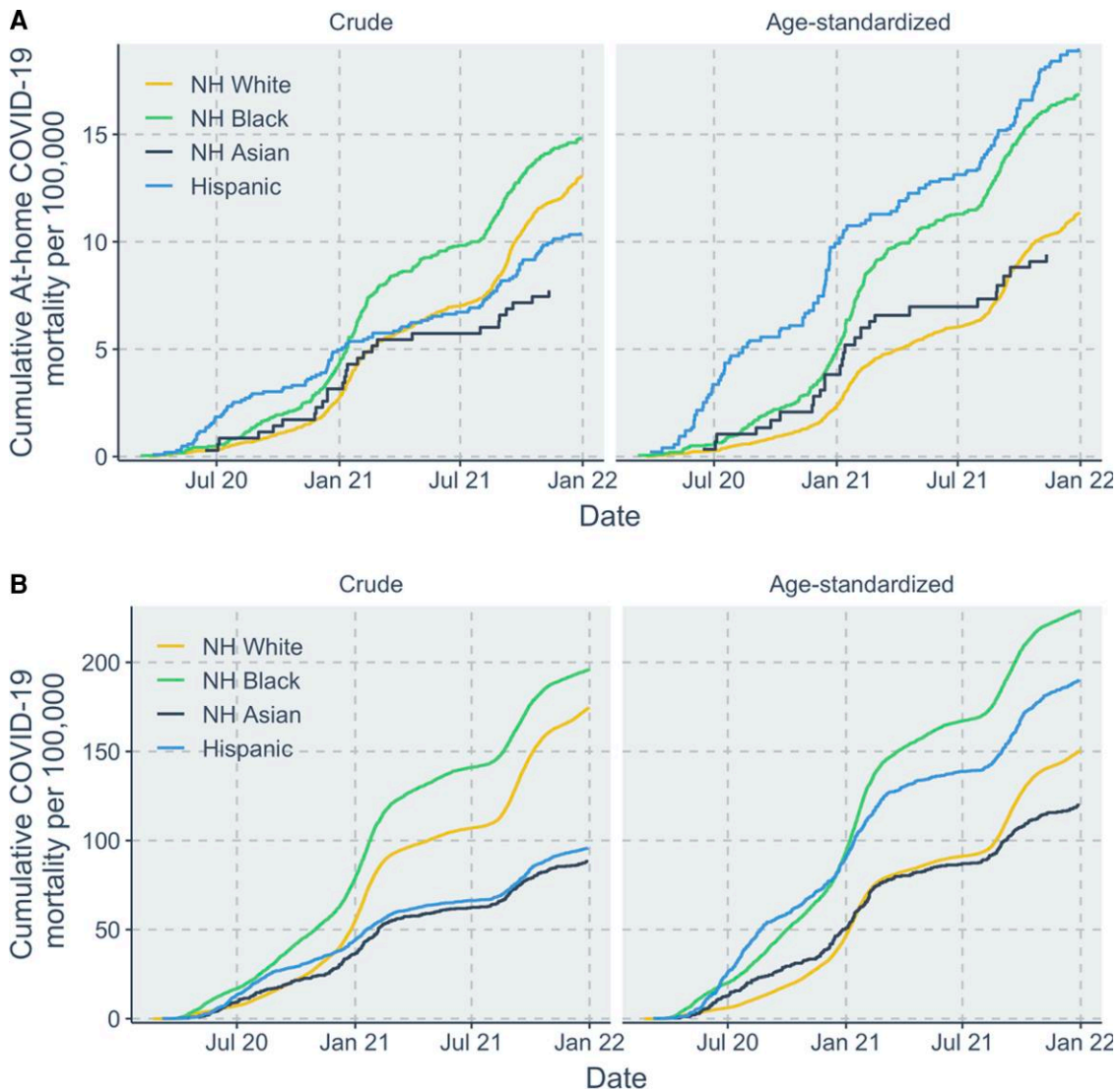


Figure 1. Crude and age-standardized at-home coronavirus disease 2019 (COVID-19) mortality (A) and overall COVID-19 mortality (B) by race/ethnicity, North Carolina, March 1, 2020 through December 31, 2021. NH, non-Hispanic.

and non-Hispanic Blacks overlay the economic toll of lost work many in these populations experienced during the pandemic, and the health insurance it provides. Such economic concerns have been well documented as a driver of health disparities in the United States [5]. It should also be noted that like many of its neighbors in the US south, North Carolina has not expanded eligibility for Medicaid, the public insurance program that provides healthcare coverage to low-income families and individuals. According to the NCDHHS, Medicaid expansion would provide affordable healthcare insurance to at least 600 000 people in the state [6].

That Hispanic people, after standardizing for age, were more at risk of dying at home than non-Hispanic Black people requires greater study. The immigration status of those diagnosed with and dying from COVID-19 was unavailable; therefore, it is

unclear the extent to which fear of arrest among unauthorized persons prevented healthcare seeking by some in this population; approximately, 23% of the 1.2 million Hispanic people in North Carolina are unauthorized immigrants [7, 8]. Other barriers, including language and cultural considerations specific to and beyond COVID-19 may also have contributed to the higher risk for at-home death among Hispanics.

Not unexpectedly, given their increased risk for severe COVID-19, people 70 years of age and older comprised the majority of those dying at home; however, approximately 40% were younger. Among at-home deaths, 14% were younger than 55 years, although only 7% of COVID-19 deaths overall in the state occurred in those below this age.

Coronavirus disease 2019 vaccination prevents infection and progression to severe disease among those who become

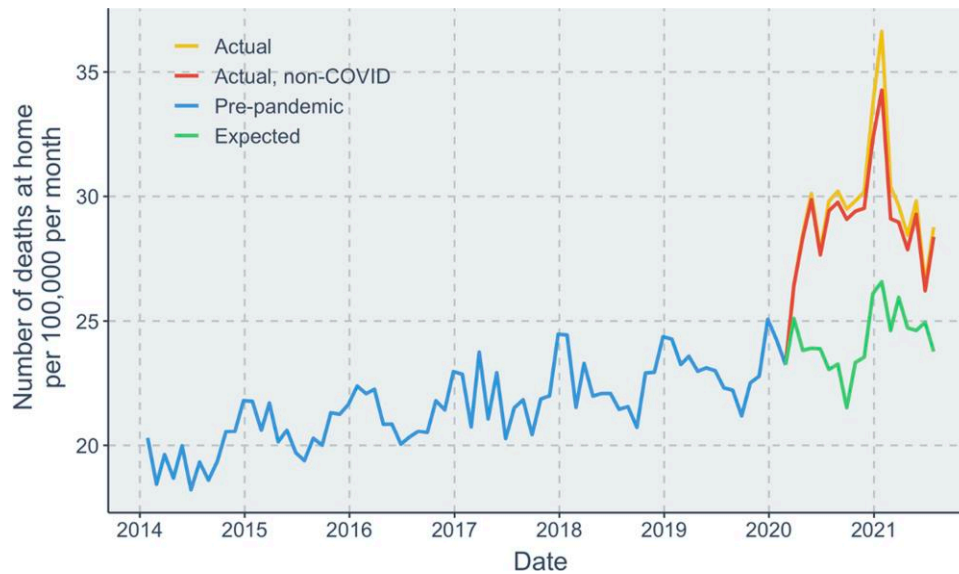


Figure 2. Prepandemic, expected, and actual numbers of deaths from any cause occurring at home per 100 000 people per month, North Carolina, January 1, 2014–July 31, 2021. COVID-19, coronavirus disease 2019.

infected. Vaccines for COVID-19 became available in December 2020 and was initially restricted to older individuals before criteria were serially expanded to others. Racial and ethnic differences in the uptake of COVID-19 vaccines in North Carolina developed early after COVID-19 vaccine rollout and persisted through 2021, albeit narrowing over the course of the year [9]. By November 2021, the proportion of Hispanic people living in North Carolina who had completed the initial vaccine series equaled the proportion of White people living in the state who had completed the vaccine series, which was 48% in each. However, at the end of 2021, completion of the initial vaccination remained 5% lower than that of White residents. Although, we observed differences by race and ethnicity in COVID-19 mortality in general and at-home before vaccines became available, differential COVID-19 vaccination, including booster doses, is now another important factor to consider when exploring these disparities.

It is notable that Hispanic and non-Hispanic Black North Carolinians have had lower overall rates of dying at home from any cause compared to non-Hispanic White people before and even during the pandemic (Supplemental Figures 1 and 2). During COVID-19, monthly rates of dying at home from any cause rose for all groups but remained lower for Hispanic people than for non-Hispanic White and Black North Carolinians. Differences in preferences for intensity and setting of end-of-life care by race and ethnicity have been described [10]; however, these preferences are most typically expressed at the late stage of a chronic illness, rather than an acute, progressive infectious disease [11]. Our finding of a dramatic increase in any-cause at-home deaths during the

pandemic suggests barriers to urgently needed care were common but were greatest for Hispanic individuals with severe COVID-19.

There are limitations that should be considered when interpreting these findings. The data used for the analyses were based on ICD-10 coding recorded on death certificates, the same methodology used by the Centers for Disease Control and Prevention; however, the assignment of cause(s) of death and of race and ethnicity were reliant on those completing the certificate. These data do not include COVID-19 vaccination status. Furthermore, our analyses are centered on North Carolina, and although our findings may be applicable to other states with similar demographics and healthcare availability, they are not expected to be generalizable to all states in the United States. Finally, the available data, although providing evidence of differences in at-home COVID-19 death by race and ethnicity, are limited in their ability to identify their causes. Putative explanatory factors accounting for the disparities we observed are likely to be multiple and complex, and our work calls for additional investigations to better understand these forces and identify strategies to mitigate their lethal effects.

CONCLUSIONS

In conclusion, our findings indicate that throughout the COVID-19 pandemic, the age-adjusted risk for dying from COVID-19 at home was greatest for persons of color, especially Hispanic people. Pandemic-related hurdles likely increased rates of dying at-home from any cause and exacerbated existing factors that act as barriers to care and prevent those dying due to

COVID-19 from accessing proper medical attention. Approaches that remove these barriers, extend healthcare access, and encourage healthcare seeking behaviors, particularly for those disproportionately impacted by both COVID-19 and impediments to healthcare, are needed to avoid preventable deaths.

Supplementary Data

Supplementary materials are available at *Open Forum Infectious Diseases* online. Consisting of data provided by the authors to benefit the reader, the posted materials are not copyedited and are the sole responsibility of the authors, so questions or comments should be addressed to the corresponding author.

Acknowledgments

We thank Dr. Sonia Napravnik for analytical guidance and advice.

Potential conflicts of interest. All authors: No reported conflicts of interest. All authors have submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest.

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