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Identification of Deaths With Post-acute Sequelae of COVID-19 From Death Certificate Literal Text: United States, January 1, 2020–June 30, 2022

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Abstract

Objectives—This study describes the use of death certificate literal text to identify and quantify COVID-19 deaths with post-acute sequelae of COVID-19 (PASC), or long COVID, in the National Vital Statistics System (NVSS).

Methods—Data are based on final and provisional NVSS death certificate data for deaths occurring in the United States during January 1, 2020–June 30, 2022. Deaths were limited to those with the International Classification of Diseases, 10th Revision (ICD–10) cause-of-death code U07.1 and literal text with keywords referring to PASC or long COVID. Data are based on death records received and processed by the National Center for Health Statistics as of October 7, 2022.

Results—The analysis identified 3,544 deaths mentioning long COVID key terms and coded to U07.1, the ICD-10 code for COVID-19, among deaths occurring in the United States from January 1, 2020, through June 30, 2022. The percentage of COVID-19 deaths with long COVID peaked in June 2021 (1.2%) and in April 2022 (3.8%). The age-adjusted death rate for long COVID was 6.3 per 1 million population for the 12-month period ending in June 2022. The long COVID death rate from July 1, 2021, through June 30, 2022, was highest among adults aged 85 and over, non-Hispanic American Indian or Alaska Native people, and males. Non-Hispanic Asian people had the lowest death rate.

Keywords: long COVID • Hispanic origin • race • National Vital Statistics System

Introduction

People with a history of severe COVID-19 illness are at increased risk of post-acute sequelae of COVID-19 (PASC) and death (1). PASC, commonly known as long COVID, refers to longterm symptoms experienced after a person has recovered from acute infection with SARS-CoV-2, the virus that causes COVID-19 (2). In September 2020, the World Health Organization approved the International Classification of Diseases, 10th Revision (ICD-10) mortality code U09.9 for coding and reporting post-COVID conditions linked with preceding acute COVID-19 (3,4). At the time of this analysis, code U09.9 had not been implemented for the coding and reporting of long COVID deaths in the United States, so it is not possible to assess long COVID mortality using ICD-10 codes. The results of this study will inform implementation of U09.9 in the United States. In the meantime, literal text, or the words describing the cause of death on a death certificate, can be used to enhance mortality surveillance beyond the general classification provided by ICD-10 coding (5). This study describes the use of death certificate literal text to identify and quantify COVID-19 deaths with long COVID in the National Vital Statistics System (NVSS).

Data Source and Methods

Data and methods

This report analyzed final 2020 and provisional 2021–2022 NVSS death certificate data for deaths occurring in the United States during January 1, 2020-June 30, 2022. The analysis was limited to deaths with U07.1 (COVID-19) as a contributing or underlying cause, as coded by the National Center for Health Statistics (NCHS) according to ICD-10, which details disease classification and the designation of underlying cause of death (3,6). Long COVID deaths were identified from death certificate literal text of COVID-19 deaths using the key terms "chronic COVID," "long COVID," "long haul COVID," "long hauler COVID," "post-acute sequelae of COVID-19," "postacute sequelae SARS-CoV-2 infection," "PASC," "post COVID," and "post COVID syndrome." The list of key terms used to categorize long COVID deaths was developed by consulting subject matter experts and Centers for Disease Control and Prevention clinical guidance for PASC (2).

COVID-19 death counts and rates include deaths for which COVID-19 is listed on the death certificate as an underlying or contributing cause of death. The underlying cause of death is the disease or injury that initiated the sequence of morbid events leading directly to death. COVID-19 was the underlying cause for 88.2% of COVID-19—associated deaths in the study period, and a contributing cause of death for the remaining 11.8% of such

deaths. NVSS data in this report include all deaths occurring in the 50 states, District of Columbia, and New York City, which includes residents of foreign countries and U.S. territories. During the period of analysis, 0.2% of COVID-19 deaths occurred among foreign residents and residents of U.S. territories.

To describe the trend in deaths during the study period, the number of deaths was calculated for each month for deaths with COVID-19 as an underlying or contributing cause and for all long COVID deaths. The percentage of long COVID deaths was calculated by dividing the number of long COVID deaths by the total number of COVID-19 deaths.

To tabulate the rate of COVID-19 deaths and long COVID deaths, a subsample was analyzed for deaths occurring from July 1, 2021, through June 30, 2022. Rates were calculated using the July 1, 2021, monthly postcensal population estimates based on the 2010 decennial census. Rates are reported per 1 million standard population (7). Age-adjusted death rates were calculated for deaths by sex as well as race and ethnicity, categorized as Hispanic, non-Hispanic White, non-Hispanic Black, non-Hispanic Asian, non-Hispanic American Indian or Alaska Native (AIAN), non-Hispanic Native Hawaiian or Other Pacific Islander (NHOPI), non-Hispanic people of more than one race (multiracial), and unknown. Crude death rates were calculated by age. Race and ethnicity were unknown for 848 deaths (0.2%). No records had unknown sex or age.

Rates and significance testing

Crude and age-adjusted rates are calculated as the number of deaths per 1 million U.S. 2000 standard population and include all ages. Pairwise comparisons between demographic characteristics were performed at the 0.05 level of significance. A more detailed explanation of rate computations and significance testing is available elsewhere (8). Unless otherwise specified, comparisons made in the text among rates are statistically significant.

Results

Percentage of COVID-19 deaths with long COVID

From January 1, 2020, through June 30, 2022, 3,544 COVID-19 deaths had literal text in the death certificate mentioning long COVID (or related terms), representing 0.3% of the 1,021,487 deaths with COVID-19 coded to U07.1 (the ICD-10 code for COVID-19) as an underlying or contributing cause of death in the same time period. Overall, 88.2% of COVID-19 deaths had COVID-19 as the underlying cause, and 67.5% of long COVID deaths had COVID-19 as the underlying cause (Table). The term most commonly mentioned on death certificates with long COVID was "post COVID," which was mentioned in 89.6% of long COVID deaths. The highest number of deaths with long COVID occurred in February 2022 (n = 393/3,544) (Figure 1). The percentage of COVID-19 deaths with long COVID peaked in June 2021 (1.2%) and April 2022 (3.8%) (Table 1). Both peaks coincide with periods of declining numbers of COVID-19 deaths.

Table. Underlying causes of long COVID deaths, by percentage of deaths: United States, January 1, 2020–June 30, 2022

Underlying cause	Percent
COVID-19	67.5
Heart disease	8.6
Cancer	2.9
Alzheimer disease	2.7
Chronic lower respiratory	
diseases	2.5
Diabetes	2.0
Stroke	1.8
Unintentional injury	0.8
Hypertension	0.7
Parkinson disease	0.5
Other causes of death	10.1

NOTES: National Vital Statistics System provisional data for 2021 and 2022 are incomplete. These data include deaths that occurred in the United States and may include residents of U.S. territories and foreign countries. Long COVID deaths are defined as having *International Classification of Diseases*, 10th Revision (ICD-10) code U07.1 listed as an underlying or contributing cause of death and death certificate keywords mentioning long COVID.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

Deaths by demographic characteristics

The distribution of deaths by sex differed when comparing long COVID deaths and overall COVID-19 deaths occurring during the 12-month period from July 1, 2021, through June 30, 2022. Males accounted for a larger percentage of COVID-19 deaths (56.0%) than females (44.0%). In contrast, long COVID deaths were more similar between males (51.5%) and females (48.5%) (Table 2).

The highest percentage of COVID-19 deaths occurred among people aged 65–74 (23.8%) and 75–84 (23.5%), followed by those aged 50–64 (22.6%). In contrast, people aged 75–84 accounted for the highest percentage of long COVID deaths by age (28.8%), followed by those aged 85 and over (28.1%) and 65–74 (21.5%).

The majority of long COVID deaths occurred among non-Hispanic White people (78.5%). Non-Hispanic Black people accounted for the next highest percentage of long COVID deaths (10.1%), followed by Hispanic people (7.8%). Non-Hispanic AIAN, non-Hispanic Asian, and non-Hispanic multiracial people accounted for less than 2% of long COVID deaths per group.

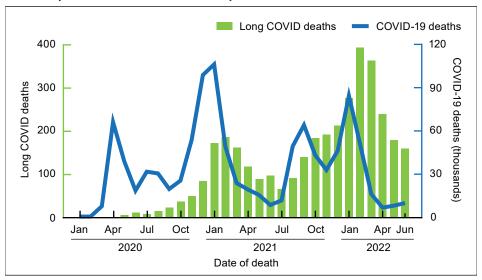
Crude and age-adjusted death rates

Death rates were calculated for deaths occurring in the 12-month period ending in June 2022. The age-adjusted death rate for long COVID was 6.3 per 1 million for this period (Table 2).

By sex and age

The age-adjusted death rate for long COVID was 7.3 per 1 million for males and 5.5 for females. Among the groups for which a reliable rate could be calculated, the age-specific death rate for long COVID increased with increasing age and was lowest among people aged 30–39 (0.9) and highest among those aged 85 and over (117.1), similar to the pattern for all COVID-19 deaths.

Figure 1. Provisional number of deaths with COVID-19 and deaths mentioning long COVID, by month and year of death: United States, January 1, 2020–June 30, 2022



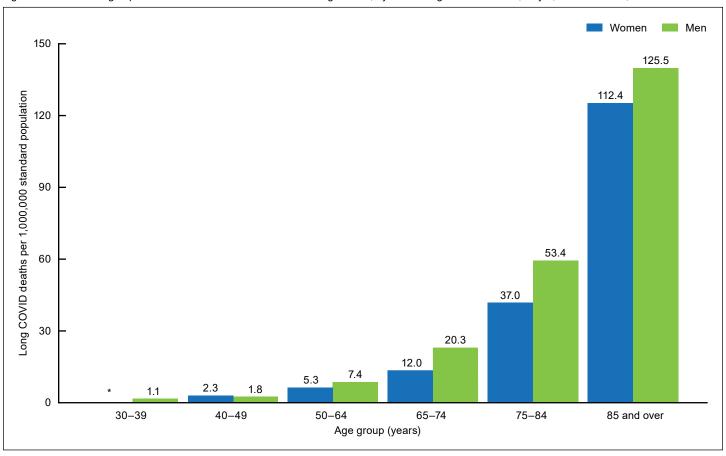
NOTES: National Vital Statistics System provisional data for 2021 and 2022 are incomplete. Data for 2020 are final. These data include deaths that occurred in the United States and may include residents of U.S. territories and foreign countries. Deaths with confirmed or presumed COVID-19 as an underlying or contributing cause of death were identified using *International Classification of Diseases*, 10th Revision code U07.1 and death certificate keywords mentioning long COVID. SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

Death rates for men were higher than women for all age groups over age 50 (Figure 2). In accordance with NCHS standards for reliability, sex-specific long COVID death rates could not be calculated for age groups that had fewer than 20 deaths each: males and females aged 0–4 years, 5–17, and 18–29, and females aged 30–39. The death rate was lower for men aged 40–49 (1.8 per 1 million) than women of the same age group (2.3), although this difference was not significant.

By race and ethnicity

The age-adjusted death rate for long COVID was highest among non-Hispanic AIAN people (14.8 per 1 million) and lowest among non-Hispanic Asian people (1.5) (Figure 3). The death rate for long COVID was 6.7 for non-Hispanic White

Figure 2. Provisional age-specific rates for COVID-19 deaths with long COVID, by sex and age: United States, July 1, 2021–June 30, 2022



^{*} Estimate does not meet National Center for Health Statistics standards of reliability.

NOTES: National Vital Statistics System provisional data for 2021 and 2022 are incomplete. These data include deaths that occurred in the United States and may include residents of U.S. territories and foreign countries. Deaths with confirmed or presumed COVID-19 as an underlying or contributing cause of death were identified using *International Classification of Diseases*, 10th Revision code U07.1 and death certificate keywords mentioning long COVID.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

people, 6.4 for non-Hispanic Black people, and 4.7 for Hispanic people. Patterns by race and ethnicity groups were not necessarily consistent with all COVID-19 death rates, where rates were higher among non-Hispanic Black (1,311.7) and Hispanic (1,157.1) people in addition to non-Hispanic AIAN people (1,795.0). Long COVID death rates were not calculated for non-Hispanic NHOPI and non-Hispanic multiracial people as well as those of unknown race and ethnicity due to small counts.

Discussion

During January 1, 2020–June 30, 2022, about 3,544 COVID-19 death certificates, or 0.3%, had literal text indicating long COVID as an underlying or contributing cause of death. The age-adjusted death

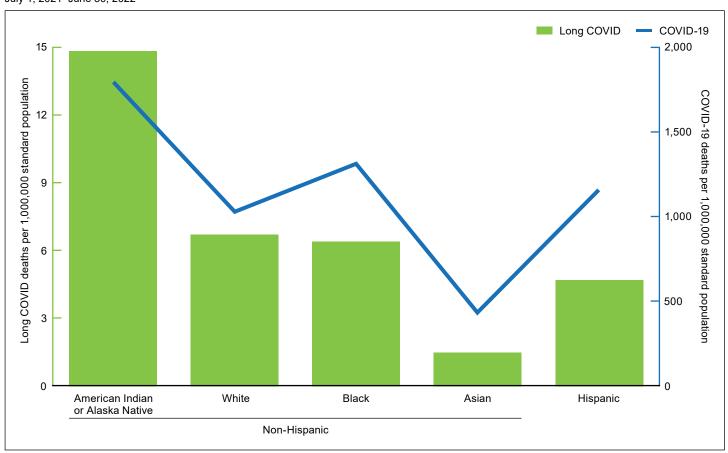
rate for long COVID was 6.3 per 1 million population for the 12-month period ending in June 2022. The long COVID death rate was highest among adults aged 85 and over, non-Hispanic AIAN people, and males.

The key terms used to categorize long COVID deaths indicate long-term symptoms or effects of prior infection, such as exacerbation of existing conditions due to COVID-19 infection (2). Some certificates included terms referring to COVID-19 with no indication of a post-COVID condition; these were not included in the counts of long COVID deaths. Only terms that communicated that a post-COVID condition caused or contributed to the death were included.

Long COVID death rate patterns by race and ethnicity differed from patterns in COVID-19 death rates for some race

and ethnicity groups. COVID-19 death rates were highest among non-Hispanic NHOPI and non-Hispanic AIAN people, while long COVID death rates were highest among non-Hispanic AIAN people. Despite having higher COVID-19 mortality rates, non-Hispanic Black and Hispanic people did not have higher long COVID death rates than non-Hispanic White people—rates were similar for non-Hispanic White and non-Hispanic Black people. These differences may be due to higher mortality among non-Hispanic Black and Hispanic populations, resulting in fewer COVID-19 survivors left to experience long COVID conditions. Low rates of long COVID among non-Hispanic Black and Hispanic people may also be due to poor access to health care and appropriate diagnosis and reporting of post-COVID conditions in these populations (9,10).

Figure 3. Provisional age-adjusted death rates for COVID-19 and COVID-19 deaths with long COVID, by race and Hispanic origin: United States, July 1, 2021–June 30, 2022



NOTES: National Vital Statistics System provisional data for 2021 and 2022 are incomplete. These data include deaths that occurred in the United States and may include residents of U.S. territories and foreign countries. Deaths with confirmed or presumed COVID-19 as an underlying or contributing cause of death were identified using *International Classification of Diseases*, 10th Revision code U07.1 and death certificate keywords mentioning long COVID. Deaths for non-Hispanic Native Hawaiian or Other Pacific Islander people, non-Hispanic multiracial people, and people of unknown race have fewer than 20 deaths and are not presented in this figure.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

The findings in this report are subject to at least five limitations. First, data for 2021 and 2022 are provisional, and numbers and rates may change as additional information is received. Described changes in mortality trends, death counts, and rates may be underestimates. Second, timeliness of death certificate submission can vary by jurisdiction. As a result, the national distribution of deaths might be affected by the distribution of deaths reported from jurisdictions reporting later, which may differ from those in the United States overall. Third, certain categories of race (as in AIAN and Asian) and Hispanic ethnicity have been shown to incur some misclassification on death certificates (11). As a result, death rates for some groups may be under- or overestimated. Fourth, the study may underestimate long COVID deaths because clinical guidance for the identification and reporting of PASC has evolved over time and death certificate literal text may contain additional key terms that were not included in this study. Fifth, the investigation only included death certificates that listed COVID-19 as a cause of death, and as a result may underestimate deaths where prior COVID-19 infection was not confirmed or suspected but may have contributed to the death.

This study uses literal text from death certificates to identify and quantify long COVID deaths and represents the first attempt at quantifying long COVID deaths in national vital statistics data. Understanding the key terms used to describe long COVID on the death certificate helps analysts quantify long COVID deaths and can help inform official guidance to death certifiers to ensure that long COVID is being consistently reported on death certificates. Standardizing the reporting of causes of death such as long COVID helps to accurately quantify novel and emerging public health concerns. The implementation of ICD-10 code U09.9 for cause-of-death coding and standardized guidance for certification of these deaths would facilitate more rapid ongoing surveillance of long COVID deaths.

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Table 1. Provisional death counts for COVID-19 and long COVID, by death month and year: United States, January 1, 2020–June 30, 2022

	COVID-19	Long COVID		
Date of death	Count	Count	Percent COVID-19 deaths	
Total	1,021,487	3,544	0.3	
2020				
January	6	0	0.0	
February	25	0	0.0	
March	7,172	0	0.0	
April	65,547	1	0.0	
May	38,330	5	0.0	
June	18,025	11	0.1	
July	31,135	8	0.0	
August	29,912	15	0.1	
September	19,157	22	0.1	
October	24,929	37	0.1	
November	53,246	49	0.1	
December	98,171	84	0.1	
2021				
January	105,565	172	0.2	
February	48,569	186	0.4	
March	23,265	161	0.7	
April	18,805	117	0.6	
May	14,989	89	0.6	
June	8,023	97	1.2	
July	11,222	65	0.6	
August	48,821	91	0.2	
September	63,446	139	0.2	
October	42,607	183	0.4	
November	32,329	191	0.6	
December	45,626	212	0.5	
2022				
January	83,796	276	0.3	
February	50,075	393	0.8	
March	15,539	363	2.3	
April	6,215	239	3.8	
May	7,557	179	2.4	
June	9,383	159	1.7	
ound	9,000	100	1.7	

NOTES: National Vital Statistics System provisional data for 2021 and 2022 are incomplete. These data include deaths that occurred in the United States and may include residents of U.S. territories and foreign countries. COVID-19 deaths are defined as deaths with International Classification of Diseases, 10th Revision (ICD-10) code U07.1 listed as an underlying or contributing cause of death. Long COVID deaths are defined as having ICD-10 code U07.1 and death certificate keywords mentioning long COVID.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

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Table 2. Provisional death rates for COVID-19 and long COVID, by demographic characteristics: United States, July 1, 2021–June 30, 2022

Characteristic	COVID-19			Long COVID		
	Count	Rate per 1,000,000	Percent COVID-19 deaths	Count	Rate per 1,000,000	Percent long COVID-19 deaths
Total	416,616	1,052.8	100.0	2,490	6.3	100.0
Age group (years)						
0–4	381	20.2	0.1	1	*	0.0
5–17	487	8.9	0.1	2	*	0.1
18–29	3,962	75.5	1.0	11	*	0.4
30–39	11,475	252.7	2.8	39	0.9	1.6
40–49	24,794	606.4	6.0	83	2.0	3.3
50–64	94,099	1,477.0	22.6	402	6.3	16.1
65–74	98,993	2,940.4	23.8	535	15.9	21.5
75–84	98,033	6,049.2	23.5	717	44.2	28.8
85 and over	84,392	14,122.4	20.3	700	117.1	28.1
Sex						
Female	183,237	841.1	44.0	1,208	5.5	48.5
Male	233,379	1,312.2	56.0	1,282	7.3	51.5
Race and ethnicity						
HispanicNon-Hispanic: American Indian or	52,050	1,157.1	12.5	193	4.7	7.8
Alaska Native	4.438	1.795.0	1.1	37	14.8	1.5
Asian	8,773	431.9	2.1	29	1.5	1.2
Black	53,261	1,311.7	12.8	252	6.4	10.1
More than one race	1.924	475.1	0.5	18	*	0.7
Native Hawaiian or	1,021	11 0.1	0.0	.0		
Other Pacific Islander	1.060	1.823.0	0.3	2	*	0.1
White	294,262	1,028.1	70.6	1,955	6.7	78.5
Unknown	848	*	0.2	4	*	0.2

^{*} Estimate does not meet National Center for Health Statistics standards of reliability.

NOTES: National Vital Statistics System provisional data for 2021 and 2022 are incomplete. These data include deaths that occurred in the United States and may include residents of U.S. territories and foreign countries. Death rates are presented per 1,000,000 standard population. Age-adjusted death rates are provided overall and by sex and race and ethnicity. COVID-19 deaths are defined as deaths with International Classification of Diseases, 10th Revision (ICD-10) code U07.1 listed as an underlying or contributing cause of death. Long COVID deaths are defined as having ICD-10 code U07.1 and death certificate keywords mentioning long COVID.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

Technical Notes

Census population data

The population data used to estimate the death rates shown in this report are July 1, 2021, monthly postcensal population estimates based on the 2010 decennial census and are available from the U.S. Census Bureau website (7).

Cause-of-death classification

Cause of death was classified following World Health Organization regulations, which specify that member countries classify and code causes of death according to the current revision of the *International Classification of Diseases* (ICD). ICD provides the basic guidance used in virtually all countries to code and classify causes of death. Effective with deaths occurring in 1999, the United States began using the 10th revision of this classification (ICD–10) (4). COVID-19 deaths are identified by ICD–10 multiple cause-of-death code U07.1.

Computing rates

Rates for all ages combined in this report are age adjusted based on a standard 2000 population per 1,000,000 estimated U.S. population. Age-specific rates are per 1,000,000 population in the specified age group. Comparisons made in the text among rates, unless otherwise specified, are statistically significant at the 0.05 level of significance. Lack of comment in this report about any two rates does not mean that the difference was tested and found not to be significant at this level.

Random variation

The mortality data presented in this report are not subject to sampling error. Provisional mortality data may be affected by random variation—that is, the number of deaths that actually occurred may be considered as one of a large series of possible results that could have arisen under the same circumstances.

When the number of deaths is large, a normal approximation may be used in calculating confidence intervals and statistical tests. How large in terms of number of deaths is, to some extent, subjective. In general, for age-specific death rates, the normal approximation performs well when the number of deaths is 100 or greater. More information on statistical testing is published elsewhere (8).

Availability of mortality data

Mortality data used in this report are available in electronic products as described on the NCHS mortality website at: https://www.cdc.gov/nchs/deaths.htm. Final and provisional mortality data are located at: https://www.cdc.gov/nchs/nvss/vsrr.htm, and on CDC WONDER at: https://wonder.cdc.gov/mcd-icd10-provisional.html.

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