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Barriers to and Disparities in Access to Health Care Among Adults Aged ≥18 Years with Epilepsy — United States, 2015 and 2017

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Approximately 3 million U.S. adults have active epilepsy (i.e., self-reported doctor-diagnosed history of epilepsy and currently taking epilepsy medication or have had at least one seizure in the past year, or both) (*1*). One of the most common brain disorders, epilepsy poses a number of challenges for people living with this condition because its treatment can be complex, daily management might be inadequate to achieve seizure control, it limits social participation, and epilepsy is associated with early mortality.[†] Previous studies indicate that persons with epilepsy are more likely to experience barriers or delays in receipt of certain types of care, including epilepsy specialty care, and that these delays are often associated with individual factors (e.g., seizure type) or social determinants of health (e.g., household income or provider availability) (*2–4*). To obtain updated estimates of access to health care among U.S. adults aged ≥18 years by epilepsy status, CDC analyzed pooled data from the 2015 and 2017 National Health Interview Survey (NHIS), the most recent years with available epilepsy data. Age-adjusted analyses comparing adults with active epilepsy or inactive epilepsy (i.e., self-reported doctor-diagnosed epilepsy but not currently taking medication for epilepsy and have had no seizure in the past year) with adults without epilepsy indicated that adults with active or inactive epilepsy were more likely to have Medicaid or other public insurance coverage and to report an inability to afford prescription medicine, specialty care, or vision or dental care. Adults with active or inactive epilepsy were more likely to take less medication than prescribed to save money, to be in families having problems paying medical bills, and to report delaying care because of insufficient transportation. Enhancing linkages between clinical and community programs and services by public health practitioners and epilepsy health and social service providers can address gaps in access to health care.

NHIS is an annual, nationally representative household survey of the U.S. civilian, noninstitutionalized population.[§] Supplementary questions on epilepsy were added to the 2015 and 2017 Sample Adult Core component of NHIS, which includes one randomly selected adult aged ≥18 years from each randomly selected household. Adult respondents

[*] Deceased.
[†] https://www.nap.edu/read/13379/chapter/3#25
[§] https://www.cdc.gov/nchs/nhis/index.htm

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answered three questions about epilepsy to self-identify as a person with active, inactive, or no epilepsy (epilepsy status).[¶] These case-ascertainment questions have been validated for use in community surveillance (*5*). Information about access to health care and income was collected in the NHIS Sample Adult, Person, and Imputed Income files. In 2015 and 2017, a total of 33,672 adults (final response rate = 55.2%) and 26,742 adults (final response rate = 53.0%), respectively, responded to the survey.[**] CDC pooled 2015 and 2017 data (combined response rate = 54.1%) to increase the reliability of estimates.

Estimates were weighted and age-standardized to the 2000 U.S. Census Bureau projected adult population using three age groups: 18–44, 45–64, and ≥65 years.[††] Age-standardized prevalences of selected access-to-care indicators[§§] were compared between adults with active epilepsy and no epilepsy and between those with inactive epilepsy and no epilepsy. Age-standardized percentages of adults with active, inactive, and no epilepsy who were in families having problems paying medical bills in the past year were calculated by selected sociodemographic characteristics. Analyses were conducted with SAS-callable SUDAAN (version 9.4; SAS Institute) to account for the respondent sampling weights and NHIS complex sample design. All reported differences are statistically significant ($p<0.05$ by two-tailed t-tests). After excluding respondents with missing information on epilepsy history (i.e., respondents who refused to respond or responded "don't know" to the question "Have you ever been told by a doctor or other health professional that you have a seizure disorder or epilepsy?"), the final

[¶] 1) "Have you ever been told by a doctor or other health professional that you have a seizure disorder or epilepsy?" 2) "Are you currently taking any medicine to control your seizure disorder or epilepsy?" 3) "Think back to last year about the same time. About how many seizures of any type have you had in the past year?" Active epilepsy was defined as having a diagnosis of epilepsy and either taking medication, having had one or more seizures in the past year, or both. Inactive epilepsy was defined as adults who reported a history of epilepsy but were not taking medication for epilepsy and had not had a seizure in the past year. Adults with no epilepsy were those who answered no history of ever having received a diagnosis of epilepsy or seizure disorder by a doctor or health professional.

[**] https://nhis.ipums.org/nhis/resources/srvydesc2015.pdf; https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2017/srvydesc.pdf

[††] https://www.cdc.gov/nchs/data/statnt/statnt20.pdf

[§§] NHIS Person file (Family questionnaire) access-to-care indicators include insurance type; respondent or a family member having problems paying medical bills; and having medical bills that cannot be paid at all. Sample Adult file access-to-care indicators include no transportation to get to a doctor's office in the past 12 months; trouble finding a doctor/provider in the past 12 months; couldn't afford seeing a specialist in the past year; couldn't afford mental health care or counseling in the past 12 months; had an emergency department visit because of not having another place to go (among adults who had an emergency department visit in the past year); couldn't afford dental care or eyeglasses in the past 12 months; couldn't afford prescription medicine in the past 12 months; and skipped medication doses/took less/delayed filling prescription to save money in the past 12 months.

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analytical sample included 60,281 (99.0%) respondents. This activity was reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.¶¶

During 2015 and 2017, adults were less likely to be uninsured if they had active (6.5%) epilepsy compared with those without epilepsy (11.0%) (Table 1). Adults with active or inactive epilepsy were less likely to have private insurance (39.3% and 53.9%, respectively) and more likely to have Medicaid or other public health insurance coverage (44.4% and 27.3%, respectively) than were those without epilepsy (64.9% [private] and 15.6% [Medicaid or other public health insurance]). More adults with active epilepsy than without epilepsy had trouble finding a doctor or other health care provider (5.4% versus 3.1%). More adults with active epilepsy (6.9%) or inactive epilepsy (4.9%) than without epilepsy (1.7%) reported delayed care because of lack of transportation. A greater percentage of adults with active or inactive epilepsy had difficulty affording a specialist (7.5% and 7.3%, respectively) than did those without epilepsy (4.1%); a similar pattern was observed for affording mental health care.

Adults with active or inactive epilepsy were more likely to report an inability to afford prescription medicine (13.2% and 12.4%), skipping medication doses to save money (9.3% and 12.9%), delaying obtaining refills (12.2% and 14.9%), taking less than the prescribed dosages of medicine to save money (10.8% and 11.6%), and being unable to afford dental care (20.3% and 19.3%) compared with those without epilepsy (6.1%, 6.1%, 8.3%, 6.4%, and 10.7%, respectively). Adults with active epilepsy were more likely to report an inability to afford eyeglasses (12.5%) than were those without epilepsy (5.9%).

Adults with active or inactive epilepsy were overall significantly more likely to be in families having problems paying their medical bills (27.9% and 27.6%, respectively) than were

¶¶ 45 C.F.R. part 46.102(l)(2), 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

TABLE 1. Crude and age-standardized prevalences* of indicators of limitations in access to care among adults aged ≥18 years, by epilepsy status — National Health Interview Survey, United States, 2015 and 2017

	% (95% CI)					
	Active epilepsy† (n = 735)		Inactive epilepsy§ (n = 456)		No epilepsy¶ (n = 59,090)	
Characteristic	Crude	Age-standardized	Crude	Age-standardized	Crude	Age-standardized
Current insurance type						
Private	39.2 (34.4–44.2)	39.3 (34.4–44.4)**	55.6 (49.7–61.4)	53.9 (48.0–59.6)**	64.4 (63.7–65.1)	64.9 (64.2–65.6)
Medicaid/Other public††	46.6 (41.7–51.5)	44.4 (39.8–49.1)**	27.9 (22.8–33.7)	27.3 (22.2–33.0)**	15.4 (14.9–15.8)	15.6 (15.1–16.1)
Medicare	8.0 (6.1–10.5)	9.8 (8.2–11.7)	5.5 (3.7–8.1)	8.0 (6.0–10.5)	10.0 (9.6–10.3)	8.6 (8.4–8.8)
Uninsured	6.3 (4.2–9.3)	6.5 (4.4–9.7)**	10.9 (10.6–15.4)	10.8 (7.6–15.3)	10.3 (9.9–10.7)	11.0 (10.5–11.4)
Reasons for not seeking care, paying medical bills, or obtaining prescriptions when needed during the last 12 months						
Lack of transportation	7.11 (5.4–9.3)	6.9 (5.2–9.1)**	5.0 (3.3–7.6)	4.9 (3.2–7.4)**	1.8 (1.6–1.9)	1.7 (1.6–1.9)
Trouble finding provider who would see them	5.7 (3.9–8.0)	5.4 (3.7–7.8)**	4.5 (2.7–7.4)	4.4 (2.7–7.2)	3.1 (2.9–3.3)	3.1 (2.9–3.3)
Could not afford to see a specialist	7.6 (5.4–10.7)	7.5 (5.3–10.6)**	7.6 (5.2–10.9)	7.3 (5.0–10.4)**	4.1 (3.9–4.4)	4.1 (3.9–4.4)
Could not afford mental health care or counseling	4.4 (2.9–6.8)	4.4 (2.8–6.8)**	5.6 (3.2–9.4)	5.4 (3.1–9.3)**	1.9 (1.8–2.1)	2.0 (1.9–2.2)
Last ED visit because didn't have another place to go§§	36.4 (29.8–43.6)	38.4 (31.2–46.1)	44.7 (34.8–55.0)	43.7 (34.4–53.5)	39.6 (38.2–40.9)	40.3 (38.9–41.8)
Problems paying medical bills¶¶	28.4 (24.0–33.2)	27.9 (23.5–32.8)**	27.8 (22.9–33.2)	27.6 (22.7–33.1)**	13.8 (13.4–14.3)	14.0 (13.6–14.5)
Could not afford prescription medicines	13.6 (10.7–17.2)	13.2 (10.3–16.7)**	12.6 (9.6–16.3)	12.4 (9.3–16.2)**	6.1 (5.8–6.3)	6.1 (5.8–6.3)
Skipped medication doses to save money	9.7 (7.1–13.2)	9.3 (6.7–12.7)**	13.1 (9.4–18.0)	12.9 (8.9–18.2)**	5.9 (5.6–6.2)	6.1 (5.8–6.5)
Took less medicine to save money	10.5 (7.8–14.0)	10.8 (8.1–14.2)**	12.2 (8.6–16.9)	11.6 (7.9–16.6)**	6.2 (5.8–6.5)	6.4 (6.1–6.8)
Delayed filling prescription to save money	12.2 (9.4–15.6)	12.2 (9.4–15.7)**	15.4 (11.5–20.5)	14.9 (10.8–20.2)**	7.7 (7.4–8.1)	8.3 (7.9–8.7)
Could not afford dental care	20.9 (17.4–25.0)	20.3 (16.8–24.3)**	19.5 (15.4–24.5)	19.3 (15.1–24.2)**	10.7 (10.3–11.0)	10.7 (10.3–11.1)
Could not afford eyeglasses	12.9 (10.1–16.3)	12.5 (9.7–-5.9)**	10.2 (7.3–14.0)	9.6 (6.0–13.4)	6.0 (5.7–6.3)	5.9 (5.6–6.3)

Abbreviation: ED = emergency department.

* The percentage estimates are weighted. Estimates are age-standardized to the 2000 U.S. Census Bureau projected population, aged ≥18 years, using three age groups: 18–34, 35–64, and ≥65 years.

† Active epilepsy was defined as adults who answered that a doctor or health professional had ever told them they had a seizure disorder or epilepsy and also reported taking medication, having had one or more seizures in the past year, or both.

§ Inactive epilepsy was defined as adults who reported a history of epilepsy but were not taking medication for epilepsy and had not had a seizure in the past year.

¶ No epilepsy was defined as adults who answered no history of ever having been diagnosed with epilepsy or seizure disorder by a doctor or health professional.

** A t-test was conducted to compare the prevalence estimates between adults with active epilepsy and without epilepsy and between adults with inactive epilepsy and without epilepsy in the same category of indicator of access to care at the statistical significance level of 0.05 ($p<0.05$ by two-tailed t-tests).

†† Other public included state sponsored or state and federal jointly sponsored children's health insurance program and any type of military coverage with or without Medicare or other government programs.

§§ Among adults with at least one ED visit in the past year.

¶¶ Problems paying bills was defined as answering "yes" to any of the following questions: "Did you/anyone in the family have problems paying or were unable to pay any medical bills in the past 12 months?" (this could include bills for doctors, dentists, hospitals, therapists, medication, equipment, nursing home, or home care) or "Do you/does anyone in your family currently have any medical bills that you are unable to pay at all?"

TABLE 2. Numbers and age-standardized percentages* of living in a family having problems paying medical bills† in the past year among adults aged ≥18 years, by epilepsy status — National Health Interview Survey, United States, 2015 and 2017

Characteristic	Active epilepsy§ (n = 735)		Inactive epilepsy¶ (n = 456)		No epilepsy** (n = 59,090)	
	No./Total no.††	Age-standardized % (95% CI)	No./Total no.††	Age-standardized % (95% CI)	No./Total no.††	Age-standardized % (95% CI)
Total	**202/735**	**27.9 (23.5–32.8)§§**	**112/456**	**27.6 (22.7–33.1)§§**	**7,768/59,090**	**14.0 (13.6–14.5)**
Age group, yrs						
18–44	85/284	30.9 (24.1–38.6)§§	47/187	28.7 (21.1–37.8)§§	3,535/23,846	15.4 (14.7–16.0)
45–64	97/298	30.5 (24.4–37.3)§§	50/178	27.8 (20.7–36.1)§§	3,083/19,818	15.1 (14.4–15.9)
≥65	20/153	14.1 (7.2–26.0)¶¶	15/91	23.7 (14.3–36.5)§§	1,150/15,426	8.0 (7.4–8.6)
Sex						
Men	81/333	24.5 (18.2–32.2)§§	46/166	31.5 (23.0–41.3)§§	3,098/26,606	12.61 (12.0–13.2)
Women	121/402	31.4 (25.7–37.8)§§	66/290	25.5 (19.6–32.4)§§	4,670/32,484	15.4 (14.8–16.0)
Race/Ethnicity						
White, non-Hispanic	129/517	25.6 (20.5–31.6)§§	78/330	26.0 (20.5–32.4)§§	4,477/38,553	12.7 (12.2–13.2)
Black, non-Hispanic	31/99	34.3 (23.4–47.1)§§	15/ 58	42.5 (26.9–59.8)§§	1,391/7,131	20.3 (19.0–21.8)
Hispanic	23/71	34.6 (21.9–50.0)§§	15/42	40.7 (26.3–56.9)§§	1,436/8,705	16.9 (15.8–18.1)
Other***	19/48	36.7 (20.9–55.9)§§	—†††	—†††	464/4,701	10.0 (8.9–11.3)
Poverty status§§§						
<100% (of FPL)	77/227	33.9 (26.6–42.0)§§	32/107	37.7 (26.4–50.4)§§	1,646/8,807	20.5 (19.2–21.9)
≥100% to <200%	70/196	43.4 (33.3–54.0)§§	37/107	40.3 (29.9–51.7)§§	2,410/11,433	23.5 (22.4–24.6)
≥200% to <300%	32/102	36.0 (23.7–50.6)§§	21/68	32.6 (18.9–50.2)	1,571/9,697	19.0 (17.8–20.2)
≥300% to <400%	14/80	17.9 (10.3–29.3)	8/45	24.1 (11.0–45.0)¶¶	912/7,437	14.3 (13.1–15.7)
≥400%	9/130	5.1 (2.3–10.7)¶¶	14/129	15.2 (8.7–25.2)§§	1,229/21,715	6.3 (5.8–6.8)
Education level						
Less than HS graduate	40/152	30.7 (22.3–40.7)§§	20/71	30.9 (19.8–44.8)	1,321/7,440	21.1 (19.6–22.6)
HS graduate or equivalent	53/217	26.2 (18.4–35.8)§§	33/119	32.2 (22.1–44.3)§§	2,151/14,423	16.8 (15.9–17.8)
Some college or more	106/356	26.1 (20.3–32.8)§§	58/263	24.0 (18.0–31.1)§§	4,270/37,015	11.7 (11.3–12.2)
Current employment						
Yes	47/192	18.7 (12.9–26.2)	50/209	26.8 (19.6–35.6)§§	4,446/34,524	12.6 (12.0–13.1)
No	155/543	31.5 (25.8–37.7)§§	62/247	28.3 (21.4–36.4)§§	3,320/24,543	17.8 (16.9–18.7)
Marital status						
Married/Living with partner	68/268	24.9 (18.7–32.2)§§	44/188	26.1 (19.2–34.4)§§	3,706/29,705	13.2 (12.6–13.7)
Widowed/Divorced/Separated	76/240	33.7 (23.0–45.2)§§	44/145	38.1 (26.0–52.0)§§	2,340/15,911	19.4 (18.0–20.7)
Never married	57/226	26.0 (19.0–34.7)§§	24/123	24.5 (15.3–36.7)§§	1,709/13,357	13.5 (12.6–14.5)
Region						
Northeast	20/121	12.9 (6.0–25.6)¶¶	12/58	22.3 (11.0–40.2)¶¶	1,092/9,727	11.4 (10.4–12.3)
Midwest	36/161	26.1 (16.2–39.2)	32/121	29.4 (20.3–40.5)§§	1,724/13,137	15.1 (14.2–16.0)
South	97/ 287	36.3 (29.4–43.8)§§	49/163	36.3 (27.5–46.1)§§	3,251/21,005	16.6 (15.8–17.4)
West	49/166	24.1 (16.4–33.9)§§	19/114	17.2 (10.0–28.1)	1,701/15,221	11.1 (10.3–12.1)

Abbreviations: FPL = federal poverty level; HS = high school.

* The percentage estimates are weighted. Age-standardized to the 2000 U.S. Census Bureau projected population, aged ≥18 years, using three age groups: 18–44, 45–64, and ≥65 years. Estimates for age groups are not age-standardized (i.e., presented as crude percentages).

† Problem paying bills was defined as answering "yes" to any of the following questions: "Did you/anyone in the family have problems paying or were unable to pay any medical bills in the past 12 months?" (this could include bills for doctors, dentists, hospitals, therapists, medication, equipment, nursing home, or home care); or "Do you/does anyone in your family currently have any medical bills that you are unable to pay at all?"

§ Active epilepsy was defined as having a diagnosis of epilepsy and either taking medication, having had one or more seizures in the past year, or both.

¶ Inactive epilepsy was defined as adults who reported a history of epilepsy but were not taking medication for epilepsy and had not had a seizure in the past year.

** No epilepsy was defined as adults who answered no history of ever having been diagnosed with epilepsy or seizure disorder by a doctor or health professional.

†† "Total number" represents unweighted numbers of those with active epilepsy, inactive epilepsy, or no epilepsy (denominator); "number" represents unweighted numbers of those living in a family having problems paying bills among those with active epilepsy, inactive epilepsy, or no epilepsy (numerator). Some of the categories do not sum to the total (e.g., education level or marital status) and categories might not sum to the sample total because of missing responses.

§§ A t-test was conducted to compare the prevalence estimates between adults with active epilepsy and without epilepsy and between adults with inactive epilepsy and without epilepsy in the same category of characteristics at the statistical significance level of 0.05 ($p<0.05$ by two-tailed t-tests).

¶¶ Estimate is unreliable because the relative SE was >30% but <50%. Results should be interpreted with caution.

*** The Other race and ethnicity category includes other non-Hispanic groups (American Indian or Alaskan Native, Asian, multiple race, and race group not releasable).

††† Number and estimate were suppressed because denominator was <30 or relative SE was >50%.

§§§ Poverty status was defined as the ratio of family income to federal poverty level. Estimates were calculated from the National Health Interview Survey income data file.

adults without epilepsy (14%) (Table 2). Selected subgroups of adults with active or inactive epilepsy (e.g., those aged <65 years and in a family earning <200% of the federal poverty status) were also more likely to be in families having problems paying medical bills.

Discussion

Healthy People 2030 objectives include reducing the proportion of persons who cannot obtain needed medical care and reducing the proportion of persons who cannot obtain necessary prescription medicines (*6*). Persons with epilepsy need access to medical care for both epilepsy (e.g., access to antiseizure medication and neurologists) and nonepilepsy-related medical care (e.g., access to dental and vision care) to prevent comorbidity, worsening health status, and early mortality (*7*). The findings in this study indicate a broad range of barriers for both epilepsy- and nonepilepsy-related medical care that might complicate epilepsy management and increase comorbidities, hospitalizations, disability, and health care costs for those living with the disorder as well as for those with a history of epilepsy.

Consistent with a previous study based on 2010 and 2013 NHIS data, adults with active epilepsy were more likely to be insured with Medicaid or other public insurance coverage than were those without epilepsy (*3*). Medicare coverage might afford some protection against problems paying medical bills for adults with active epilepsy aged ≥65 years compared with younger adults with epilepsy who are not eligible for Medicare. However, a 2013 study found that fewer California adults with active epilepsy who had Medicare or Medicaid obtained specialized epilepsy care compared with adults with private insurance (*4*). Medicaid expansion reduced cost-related barriers to care and was associated with improvements in selected health outcomes among low-income adults with chronic disease (*8*). Medicaid coverage for those who qualify includes mandatory benefits (e.g., outpatient hospital services) and optional benefits (e.g., prescription drugs, non-emergency medical transportation, dental care, and optometry care), which vary by state. The extent to which services are covered by Medicaid might facilitate or limit access to these services for adults with active epilepsy.***

Other individual-level factors such as sex, presence of comorbidities, or health literacy and contextual factors that constitute social determinants of health (e.g., reliable transportation, provider availability or cultural competency, and lower rates of public insurance reimbursement) might also influence epilepsy care and outcomes (*4*,*9*). Although all racial and ethnic groups with active epilepsy were more likely to report having problems paying medical bills than their counterparts without epilepsy, assessing differences in problems paying medical bills within racial and ethnic groups requires more study with larger samples. Additional studies are warranted to examine health inequities associated with race and ethnicity and social determinants of health by epilepsy status. Finally, an epilepsy diagnosis earlier in life has been reported to alter neurodevelopment and might limit opportunities later in life (*10*). More studies are needed to examine the challenges faced by adults with inactive epilepsy.

The findings in this report are subject to at least five limitations. First, because NHIS is cross-sectional, causal inferences related to the association between health care access barriers and epilepsy status cannot be made. Second, estimates are based on self-reported data and might be subject to reporting bias. Third, because adults aged ≥65 years without private insurance can have both Medicare and Medicaid coverage, the percentages of adults with Medicare might include some who are eligible for Medicaid (i.e., "dually eligible"), potentially leading to an underestimate of the overall percentages with Medicaid coverage by epilepsy status. Fourth, it is not known whether problems paying medical bills reported by a respondent with active or inactive epilepsy are related to the respondent's own medical bills or those of other family members.††† Finally, because more recent data are not available, the findings from this analysis might not represent associations of these factors beyond 2017. The ongoing efforts for data modernization and enhanced linkages with electronic health records might improve availability of more data to guide public health action.

Summary

What is already known about this topic?

Adults with epilepsy are more likely to experience barriers to accessing health care than are adults without epilepsy.

What is added by this report?

In 2015 and 2017, compared with U.S. adults without epilepsy, adults with active or inactive epilepsy were more likely to report an inability to afford prescription medicine, specialty care, or other types of care, had trouble finding a doctor, delayed care because of transportation barriers, or were in families having problems paying medical bills.

What are the implications for public health practice?

Public health practitioners and epilepsy health and social service providers can enhance linkages between clinical and community programs and services to address gaps in access to health care.

*** https://www.medicaid.gov/medicaid/benefits/index.html

††† https://www.cdc.gov/nchs/data/nhis/earlyrelease/probs_paying_medical_bills_jan_2011_jun_2017.pdf

Public health practitioners and epilepsy health and social service providers can raise awareness of the CDC-supported Epilepsy Foundation Epilepsy and Seizures 24/7 Helpline, which has trained English- and Spanish-speaking information specialists available 24 hours a day by phone and email to refer persons to local community-based programs such as medication assistance programs, transportation services, and other resources.§§§ The Epilepsy Foundation also provides information to assist patients in finding epilepsy centers and specialists nationwide.¶¶¶ Addressing disparities in access to care necessitates a comprehensive approach that accounts for social determinants of health (*6*,*9*) and intervenes to reduce treatment gaps. Public health practitioners and epilepsy health and social service providers can enhance linkages between clinical and community programs and services to address gaps in access to health care.

§§§ https://www.epilepsy.com/connect/247-helpline
¶¶¶ https://www.epilepsy.com/connect/find-epilepsy-specialist

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References

1. Zack MM, Kobau R. National and state estimates of the numbers of adults and children with active epilepsy—United States, 2015. MMWR Morb Mortal Wkly Rep 2017;66:821–5. PMID:28796763 https://doi.org/10.15585/mmwr.mm6631a1
2. Kalilani L, Faught E, Kim H, et al. Assessment and effect of a gap between new-onset epilepsy diagnosis and treatment in the US. Neurology 2019;92:e2197–208. PMID:30971487 https://doi.org/10.1212/WNL.0000000000007448
3. Thurman DJ, Kobau R, Luo YH, Helmers SL, Zack MM. Health-care access among adults with epilepsy: the U.S. National Health Interview Survey, 2010 and 2013. Epilepsy Behav 2016;55:184–8. PMID:26627980 https://doi.org/10.1016/j.yebeh.2015.10.028
4. Schiltz NK, Koroukian SM, Singer ME, Love TE, Kaiboriboon K. Disparities in access to specialized epilepsy care. Epilepsy Res 2013;107:172–80. PMID:24008077 https://doi.org/10.1016/j.eplepsyres.2013.08.003
5. Brooks DR, Avetisyan R, Jarrett KM, et al. Validation of self-reported epilepsy for purposes of community surveillance. Epilepsy Behav 2012;23:57–63. PMID:22189155 https://doi.org/10.1016/j.yebeh.2011.11.002
6. Office of Disease Prevention and Health Promotion. Healthy people 2030: access to health services. Rockville, MD: US Department of Health and Human Services; 2020. https://health.gov/healthypeople/objectives-and-data/social-determinants-health/literature-summaries/access-health-services
7. Wilson DA, Malek AM, Wagner JL, Wannamaker BB, Selassie AW. Mortality in people with epilepsy: a statewide retrospective cohort study. Epilepsy Res 2016;122:7–14. PMID:26900886 https://doi.org/10.1016/j.eplepsyres.2016.01.008
8. Torres H, Poorman E, Tadepalli U, et al. Coverage and access for Americans with chronic disease under the Affordable Care Act: a quasi-experimental study. Ann Intern Med 2017;166:472–9. PMID:28114684 https://doi.org/10.7326/M16-1256
9. Szaflarski M. Social determinants of health in epilepsy. Epilepsy Behav 2014;41:283–9. PMID:24998313 https://doi.org/10.1016/j.yebeh.2014.06.013
10. Hermann B, Seidenberg M, Jones J. The neurobehavioural comorbidities of epilepsy: can a natural history be developed? Lancet Neurol 2008;7:151–60. PMID:18207113 https://doi.org/10.1016/S1474-4422(08)70018-8

Seizure- or Epilepsy-Related Emergency Department Visits Before and During the COVID-19 Pandemic — United States, 2019–2021

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Seizures, transient signs or symptoms caused by abnormal surges of electrical activity in the brain, can result from epilepsy, a neurologic disorder characterized by abnormal electrical brain activity causing recurrent, unprovoked seizures, or from other inciting causes, such as high fever or substance abuse (*1*). Seizures generally account for approximately 1% of all emergency department (ED) visits (*2,3*). Persons of any age can experience seizures, and outcomes might range from no complications for those with a single seizure to increased risk for injury, comorbidity, impaired quality of life, and early mortality for those with epilepsy (*4*). To examine trends in weekly seizure- or epilepsy-related (seizure-related) ED visits[†] in the United States before and during the COVID-19 pandemic, CDC analyzed data from the National Syndromic Surveillance Program (NSSP).[§] Seizure-related ED visits decreased abruptly during the early pandemic period. By the end of 2020, seizure-related ED visits returned almost to prepandemic levels for persons of all ages, except children aged 0–9 years. By mid-2021, however, this age group gradually returned to baseline as well. Reasons for the decrease in seizure-related ED visits in 2020 among all age groups and the slow return to baseline among children aged 0–9 years compared with other age groups are unclear. The decrease might have been associated with fear of exposure to COVID-19 infection in EDs deterring parents or guardians of children from seeking care, adherence to mitigation measures including avoiding public settings such as EDs, or increased access to telehealth services decreasing the need for ED visits (*5*). These findings reinforce the importance of understanding factors associated with ED avoidance among persons with epilepsy or seizure, the importance that all eligible persons be up to date[¶] with COVID-19 vaccination, and the need to encourage persons to seek appropriate care for seizure-related emergencies[**] to prevent adverse outcomes.

NSSP collects deidentified electronic health record data from EDs and other health care settings. ED visit data are derived from a subset of approximately 71% of the nation's nonfederal EDs (i.e., EDs not supported by the Veterans Health Administration or U.S. Department of Defense). Diagnosis codes from the *International Classification of Diseases, Ninth Revision*, *Clinical Modification* (ICD-9-CM) and *International Classification of Diseases, Tenth Revision*, *Clinical Modification* (ICD-10-CM), Systematized Nomenclature of Medicine, and relevant free-text reason for visit (chief complaint) terms were used to identify seizure-related ED visits (Supplementary Table, https://stacks.cdc.gov/view/cdc/117412) (Supplementary Box, https://stacks.cdc.gov/view/cdc/117573). All analyses were restricted to EDs that reported consistently more complete data throughout the study period (January 1, 2019–December 31, 2021); 56% of EDs sharing data with NSSP met these criteria.[††] CDC assessed trends by six age groups (0–9, 10–19, 20–39, 40–59, 60–69, and ≥70 years) and visualized age-specific trends of weekly seizure-related ED visits during 2019–2021. Using R (version 4.1.2; The R Foundation), CDC quantified change in mean weekly seizure-related ED visits during April 1–December 29 across 3 years: 2019, 2020, and 2021; results were stratified by age group and sex. Percentage change in mean weekly seizure-related ED visits was assessed by comparing 2020 data with corresponding data from 2019 and 2021. This activity was reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.[§§]

All ED visits, including seizure-related ED visits, decreased among all age groups and among both males and females during the pandemic period April 1–December 29, 2020, compared with the corresponding period in 2019 (Table). The

* Deceased.

† Analysis was limited to ED encounters. As of December 31, 2021, the median number of facilities included in the analysis was 2,031 (range = 1,986–2,038), including data from 56% of all nonfederal EDs sharing data with NSSP.

§ NSSP is a collaboration among CDC, federal partners, local and state health departments, and academic and private sector partners. NSSP receives deidentified electronic health data from 50 states representing approximately 71% of nonfederal EDs nationwide, although <50% of ED facilities from California, Hawaii, Iowa, Minnesota, Ohio, and Oklahoma currently participate in NSSP at the time of this analysis.

¶ https://www.cdc.gov/coronavirus/2019-ncov/vaccines/stay-up-to-date.html

** Includes a first-time seizure and status epilepticus, which is defined as a continuous seizure lasting >5 minutes or recurrent seizures without regaining consciousness between seizures.

†† To limit the impact of data quality on trends, all analyses were restricted to facilities with a coefficient of variation ≤40 and percentage of weekly average informative discharge diagnosis ≥75 throughout the analysis period (January 2019–December 2021) so that only consistently reporting facilities with more complete data were included. EDs that met these data quality control criteria were included in the analysis.

§§ 45 C.F.R. part 46.102(l)(2), 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

TABLE. Mean weekly seizure- or epilepsy-related emergency department visits and overall emergency department visits, by age and sex, and percentage change* — National Syndromic Surveillance Program,† United States, April 1–December 29, 2019–2021

Characteristic	Mean weekly visits, no. (95% CI)§			% Change	
	2019	2020	2021	2019–2020	2020–2021
Seizure or epilepsy ED visits					
Age group, yrs					
0–9	2,759 (2,660–2,864)	1,553 (1,504–1,593)	2,528 (2,462–2,593)	−44	63
10–19	1,893 (1,846–1,940)	1,413 (1,356–1,469)	1,749 (1,710–1,786)	−25	24
20–39	7,102 (7,037–7,165)	6,143 (5,957–6,316)	6,579 (6,478–6,680)	−13	7
40–59	6,476 (6,412–6,539)	5,701 (5,548–5,838)	5,769 (5,678–5,860)	−12	1
60–69	2,588 (2,561–2,617)	2,423 (2,373–2,467)	2,495 (2,468–2,524)	−6	3
≥70	2,641 (2,604–2,679)	2,504(2,441–2,561)	2,583 (2,557–2,613)	−5	3
Sex					
Female	11,422 (11,344–11,501)	9,327 (9,044–9,579)	10,373 (10,280–10,470)	−18	11
Male	12,128 (12,039–12,236)	10,462 (10,214–10,694)	11,387 (11,296–11,470)	−14	9
Total	**23,588 (23,429–23,739)**	**19,824 (19,295–20,311)**	**21,800 (21,614–21,969)**	**−16**	**10**
All-cause ED visits					
Age group, yrs					
0–9	162,711 (154,767–171,195)	71,131 (67,015–74,824)	142,868 (137,805–147,822)	−56	101
10–19	127,264 (123,781–130,677)	79,594 (74,870–84,171)	114,353 (111,036–117,884)	−37	44
20–39	416,652 (413,210–420,159)	336,598 (322,674–348,693)	401,671 (394,081–409,796)	−19	19
40–59	347,606 (344,299–350,816)	288,453 (278,532–297,426)	337,317 (331,750–342,781)	−17	17
60–69	157,694 (156,596–158,946)	135,574 (130,804–139,547)	161,899 (160,116–163,865)	−14	19
≥70	231,619 (230,000–233,699)	193,202 (185,523–199,808)	231,799 (229,713–233,852)	−17	20
Sex					
Female	797,473 (791,101–804,433)	593,418 (568,244–615,384)	755,769 (745,392–766,769)	−26	27
Male	651,555 (646,948–656,594)	513,365 (494,989–530,303)	636,576 (627,504–646,651)	−21	24
Total	**1,451,717 (1,441,285–1,463,581)**	**1,109,069 (1,067,564–1,148,844)**	**1,395,349 (1,374,389–1,415,093)**	**−24**	**26**

Abbreviation: ED = emergency department.

* The percentage change in visits between the surveillance and reference periods (2019 [reference] versus 2020 [surveillance] and 2020 [reference] versus 2021 [surveillance]) was calculated as (ED visits during surveillance period – ED visits during reference period)/ED visits during reference period x 100%.

† The National Syndromic Surveillance Program receives anonymized medical record information from approximately 71% of nonfederal EDs nationwide. To reduce artifactual impact from changes in reporting patterns, analyses were restricted to facilities with more consistent reporting of more complete data (coefficient of variation ≤40 and average weekly informative discharge diagnosis ≥75% complete during 2019–2021).

§ CIs were constructed using the percentile bootstrap method using 1,000 replicate samples of the weekly counts. CIs were formed using the 2.5th and 97.5th percentiles of the bootstrap distributions.

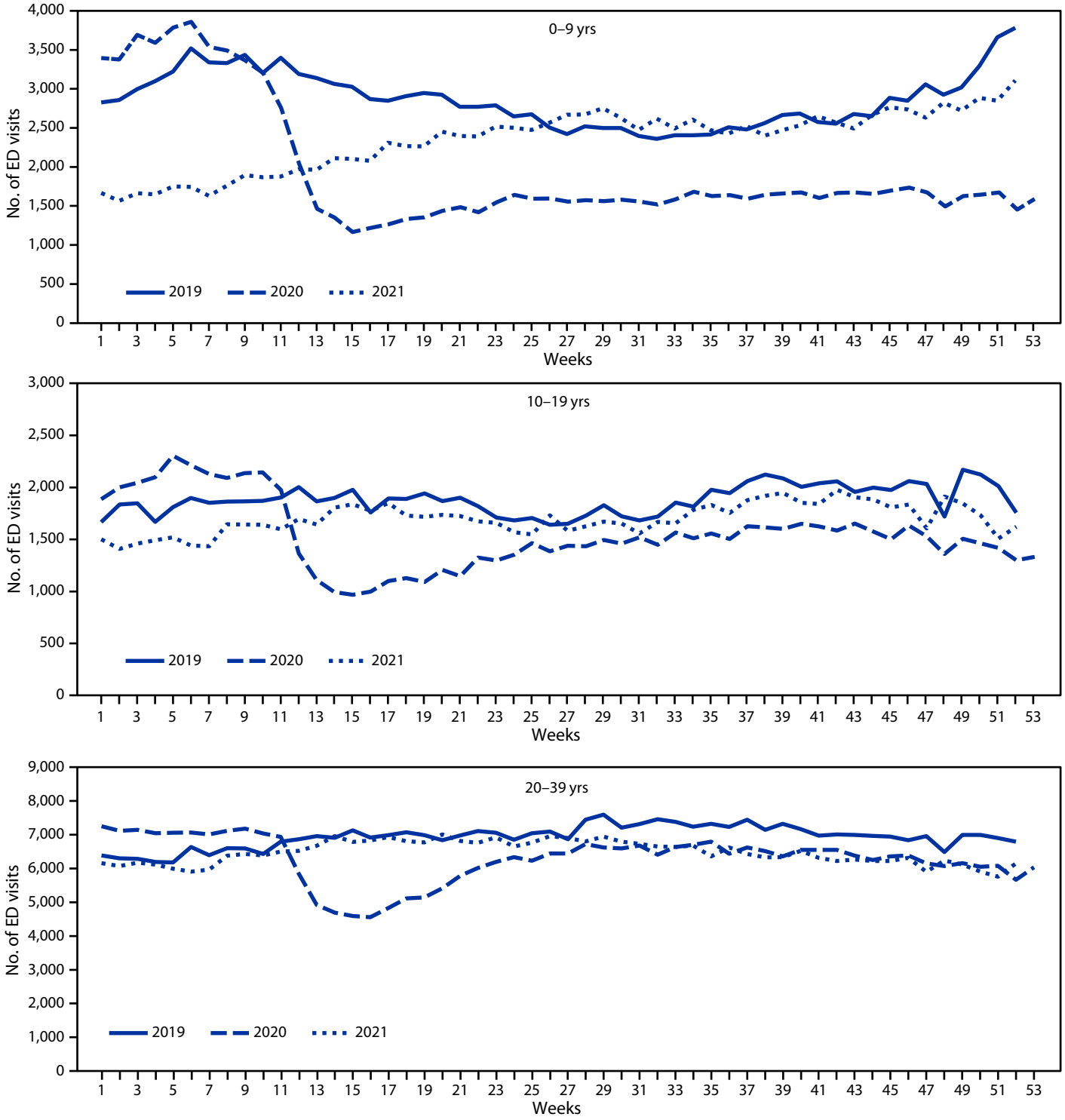
largest decline in seizure-related ED visits, noted as early as February 2020, was observed among children aged 0–9 years (Figure 1) (Figure 2). During April 1–December 29, 2020, the number of weekly seizure-related ED visits declined by 16% overall to 19,824, from 23,588 during the same period¶¶ in 2019 (Table). Among children aged 0–9 years, the number of seizure-related weekly ED visits declined by 44% to 1,553, compared with 2,759 visits during the same period in 2019; overall ED visits among children aged 0–9 years declined by 56%, from 162,711 visits in 2019 to 71,131 in 2020. By the first week of 2021, the number of seizure-related ED visits among all age groups was close to respective prepandemic levels in 2019, with the exception of children aged 0–9 years, among whom the rebound to prepandemic levels was delayed until approximately week 25 of 2021 (Figure 1). To examine whether the decrease among children aged 0–9 years was associated with pediatric febrile seizure burden, a posthoc analysis was conducted. In children aged 0–9 years, febrile seizures accounted for approximately one third of all seizure-related ED visits in all 3 years (approximately 35%, 31%, and 33% in 2019, 2020, and 2021, respectively).

¶¶ Percentage change in visits during surveillance periods compared with reference periods (surveillance period April 1–December 29, 2020, compared with reference period April 1–December 29, 2019, and surveillance period April 1–December 29, 2021, compared with reference period April 1–December 29, 2020) was calculated as (ED visits for seizures or epilepsy during surveillance period – ED visits for seizures or epilepsy during reference period)/ED visits for seizures or epilepsy during reference period x 100%.

Discussion

In this study of trends in seizure-related ED visits during the COVID-19 pandemic, seizure-related ED visits during the initial COVID-19 waves declined among all age groups, especially among children aged 0–9 years. These findings are consistent with several other studies (*6*–*8*). In one analysis of U.S. ED visits during January 2019–May 2020, the number of weekly all-cause ED visits declined abruptly during March 29–April 25, 2020, along with a decline in ED visits among children aged 0–9 years attributable to common conditions, including influenza, otitis media, upper respiratory conditions, asthma, viral

FIGURE 1. Weekly seizure- or epilepsy-related emergency department visits among persons aged <40 years, by age group* — National Syndromic Surveillance Program,† United States, 2019–2021

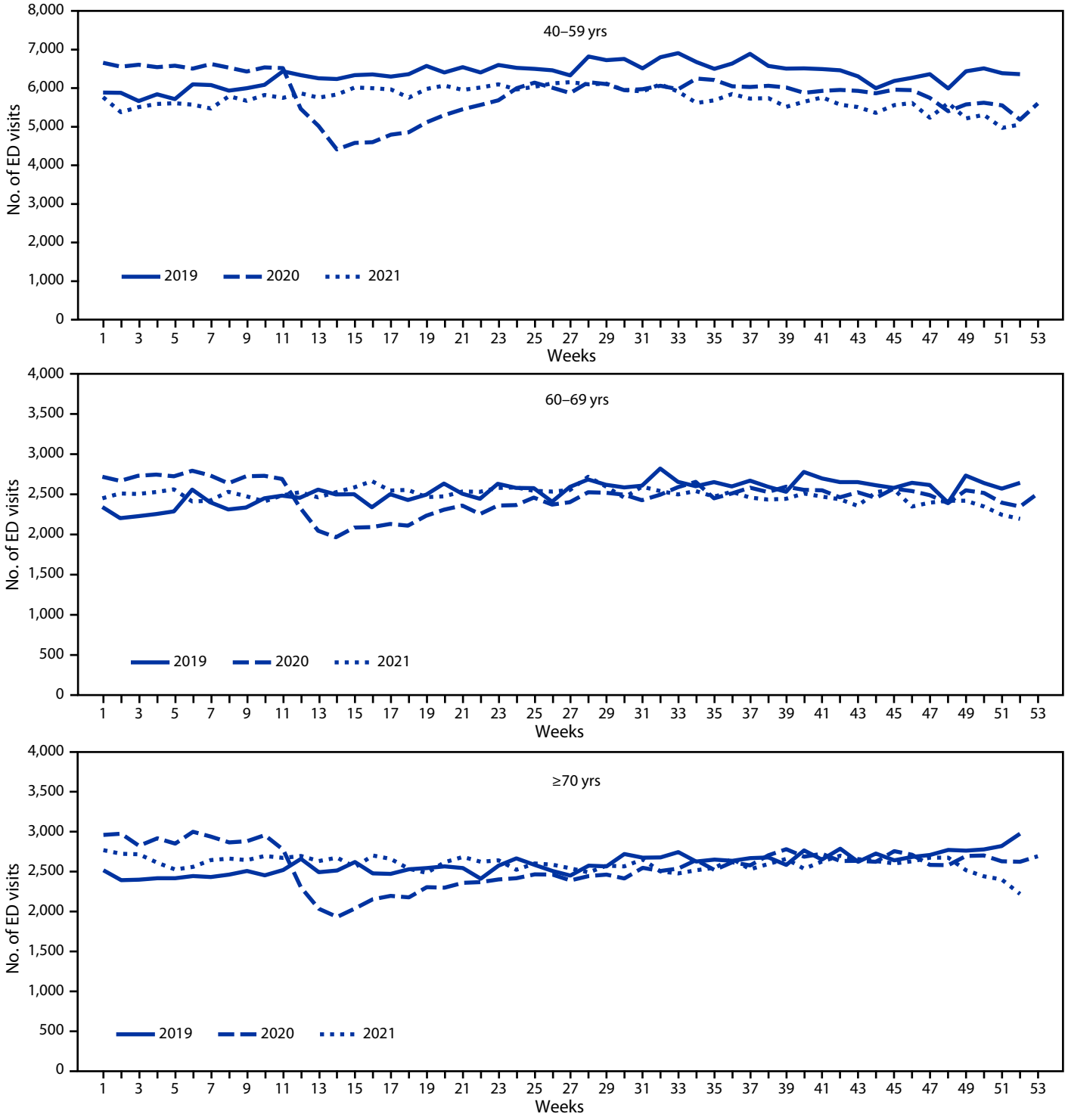


Abbreviation: ED = emergency department.

* The y-axis range differs for different age groups to account for different numbers of ED visits by these groups and to facilitate visualization of changes over time.

† The National Syndromic Surveillance Program receives deidentified medical record information from approximately 71% of nonfederal EDs nationwide. To reduce artifactual impact from changes in reporting patterns, analyses were restricted to facilities with more consistent reporting of more complete data (coefficient of variation ≤40 and average weekly informative discharge diagnosis ≥75% complete during 2019–2021).

FIGURE 2. Weekly seizure- or epilepsy-related emergency department visits among persons aged ≥40 years, by age group* — National Syndromic Surveillance Program,† United States, 2019–2021



Abbreviation: ED = emergency department.

* The y-axis range differs for different age groups to account for different numbers of ED visits by these groups and to facilitate visualization of changes over time.

† The National Syndromic Surveillance Program receives deidentified medical record information from approximately 71% of nonfederal EDs nationwide. To reduce artifactual impact from changes in reporting patterns, analyses were restricted to facilities with more consistent reporting of more complete data (coefficient of variation ≤40 and average weekly informative discharge diagnosis ≥75% complete during 2019–2021).

infection, respiratory symptoms, and fever (*6*). International studies have described a reduction in seizure-related ED visits among children during the COVID-19 pandemic, with one study reporting a notable decline in febrile seizure–related ED visits among children aged 0–6 years (*7*,*8*).

The percentages of ED visits attributable to febrile seizures among children aged 0–9 years in this study were relatively stable, therefore any changes in ED visits for febrile seizures during the study period were unlikely to explain the overall change of trend in seizure-related ED visits in this age group. Researchers in Italy examined selected causes for seizure-related ED visits during February 23–April 21, 2020 (e.g., first episode or breakthrough seizure), but could not attribute the observed decrease in seizure-related ED visits to seizure type (e.g., febrile versus first episode seizures) (*7*). However, a limitation of the Italian study was small sample size; thus, the findings warrant additional study. The findings related to febrile seizure–attributable ED use in the current report differ from, but supplement growing research in this area (*8*).

In the present study, school closures and the need to shelter at home could have facilitated heightened supervision of children while at home, including increased monitoring and promotion of healthful behaviors reducing seizure risk (e.g., medication adherence and regular sleep) or seizure sequelae (e.g., injury), thereby reducing the need for ED care (*7*,*9*). The decrease in weekly seizure-related ED visits among children aged 0–9 years might also have been associated with concern about risk for COVID-19 in EDs, deterring parents or guardians from seeking care for their children. It is also possible that expanded access and increased use of telehealth facilitated triaged telephone support or virtual health care encounters, especially for children with epilepsy and high-risk comorbidities, otherwise obtained in EDs (*5*,*10*). Additional studies are warranted to determine whether decreased in-person ED care for children with seizures or epilepsy during the initial COVID-19 pandemic was associated with any differences in risk for infection, injury, or delayed care, seizure type, or other factors and any associations between these factors and adverse outcomes.

The findings in this report are subject to at least four limitations. First, because NSSP coverage varies both within and across states, NSSP data are not nationally representative. In some states nearly all hospitals report, while in others only those in certain counties or health care systems report. Thus, these findings might not be generalizable. Second, differences in availability, coding practices, and reporting of chief complaints and discharge diagnoses from facilities might influence trends. To limit the impact of changing data volume and underlying data quality on results, only data from hospitals with consistent reporting and more complete data were included in this analysis. Third, trends displayed are restricted to ED visits only, and do not capture treatment sought for seizures in other settings. Finally, distinguishing initial seizure-related visits from subsequent visits was not possible, therefore the numbers of ED visits reported might represent multiple visits by one person.

Summary

What is already known about this topic?

Seizures or epilepsy account for 1% of annual emergency department (ED) visits. Data on seizure- or epilepsy-related ED visits during the COVID-19 pandemic are limited.

What is added by this report?

Weekly seizure- or epilepsy-related ED visits decreased sharply during the early pandemic period among all age groups, especially children aged 0–9 years. The return to prepandemic baseline in this group was delayed until mid-2021, longer than other age groups.

What are the implications for public health practice?

These findings reinforce the importance of understanding factors associated with ED avoidance among persons with epilepsy or seizure, the importance that all eligible persons be up to date with COVID-19 vaccination, and the need to encourage persons to seek appropriate care for seizure-related emergencies.

These findings reinforce the importance of understanding factors associated with ED avoidance among persons with epilepsy or seizures, and any alternative care approaches among persons with epilepsy or seizures and the need to encourage persons to seek appropriate care for seizure-related emergencies. Vaccination against SARS-CoV-2, the virus that causes COVID-19, of all age-eligible persons, including those with epilepsy, is recommended to protect against the adverse effects of COVID-19 (*9*).

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References

1. Fisher RS, Cross JH, French JA, et al. Operational classification of seizure types by the International League Against Epilepsy: position paper of the ILAE Commission for Classification and Terminology. Epilepsia 2017;58:522–30. PMID:28276060 https://doi.org/10.1111/epi.13670
2. Bank AM, Bazil CW. Emergency management of epilepsy and seizures. Semin Neurol 2019;39:73–81. PMID:30743294 https://doi.org/10.1055/s-0038-1677008
3. Pallin DJ, Goldstein JN, Moussally JS, Pelletier AJ, Green AR, Camargo CA Jr. Seizure visits in US emergency departments: epidemiology and potential disparities in care. Int J Emerg Med 2008;1:97–105. PMID:19384659 https://doi.org/10.1007/s12245-008-0024-4
4. Koh HK, Kobau R, Whittemore VH, et al. Toward an integrated public health approach for epilepsy in the 21st century. Prev Chronic Dis 2014;11:E146. PMID:25167091 https://doi.org/10.5888/pcd11.140270
5. Cross JH, Kwon CS, Asadi-Pooya AA, et al.; ILAE Task Forces on COVID-19, Telemedicine. Epilepsy care during the COVID-19 pandemic. Epilepsia 2021;62:2322–32. PMID:34428314 https://doi.org/10.1111/epi.17045
6. Hartnett KP, Kite-Powell A, DeVies J, et al.; National Syndromic Surveillance Program Community of Practice. Impact of the COVID-19 pandemic on emergency department visits—United States, January 1, 2019–May 30, 2020. MMWR Morb Mortal Wkly Rep 2020;69:699–704. PMID:32525856 https://doi.org/10.15585/mmwr.mm6923e1
7. Davico C, Marcotulli D, Lux C, et al. Where have the children with epilepsy gone? An observational study of seizure-related accesses to emergency department at the time of COVID-19. Seizure 2020;83:38–40. PMID:33080483 https://doi.org/10.1016/j.seizure.2020.09.025
8. Chiu TGA, Leung WCY, Zhang Q, et al. Changes in pediatric seizure-related emergency department attendances during COVID-19 - a territory-wide observational study. J Formos Med Assoc 2021;120:1647–51. PMID:33248859 https://doi.org/10.1016/j.jfma.2020.11.006
9. CDC. Guidance for COVID-19 prevention in K–12 schools. Atlanta, GA: US Department of Health and Human Services, CDC; 2021. Accessed February 25, 2022. https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/k-12-guidance.html
10. Kikuchi K, Hamano SI, Horiguchi A, et al. Telemedicine in epilepsy management during the coronavirus disease 2019 pandemic. Pediatr Int (Roma) 2022;64:e14972. PMID:34460985 https://doi.org/10.1111/ped.14972

Multistate Outbreak of *Listeria monocytogenes* Infections Linked to Queso Fresco — United States, 2021

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Listeriosis is a serious infection usually caused by eating food contaminated with the bacterium *Listeria monocytogenes.* An estimated 1,600 persons become ill with listeriosis each year, among whom approximately 260 die. Persons at higher risk for listeriosis include pregnant persons and their newborns, adults aged ≥65 years, and persons with weakened immune systems. Persons with invasive listeriosis usually report symptoms starting 1–4 weeks after eating food contaminated with *L. monocytogenes;* however, some persons who become infected have reported symptoms starting as late as 70 days after exposure or as early as the same day of exposure (*1*). On January 29, 2021, PulseNet, the national molecular subtyping surveillance network coordinated by CDC, identified a multistate cluster of three *L. monocytogenes* infections: two from Maryland and one from Connecticut (*2*). CDC, the Food and Drug Administration (FDA), and state and local partners began an investigation on February 1, 2021. A total of 13 outbreak-related cases were eventually identified from four states. All patients reported Hispanic ethnicity; 12 patients were hospitalized, and one died. Rapid food testing and record collection by regulatory agencies enabled investigators to identify a brand of queso fresco made with pasteurized milk as the likely source of the outbreak, leading to an initial product recall on February 19, 2021. Queso fresco and other similar fresh, soft cheeses made with pasteurized milk are a well-documented source of listeriosis outbreaks. These cheeses can be contaminated with *L. monocytogenes* unless stringent hygienic controls are implemented, and the processing environment is monitored for contamination (*3*). U.S. public health agencies should establish or improve communications, including new methods of disseminating information that also effectively reach Hispanic populations, to emphasize the risk from eating queso fresco and other similar fresh, soft cheeses, even those made with pasteurized milk.

Investigation and Results

On February 1, 2021, CDC notified state and federal partners of three listeriosis illnesses from Maryland (two cases) and Connecticut (one case) uploaded to PulseNet within the previous 120 days that were highly related (i.e., within four alleles by whole genome sequencing [WGS]). Specimen collection dates ranged from October 20, 2020, to January 6, 2021. All three patients were hospitalized; no deaths were reported. Patients were aged 45–69 years, and one patient was female. All three patients reported Hispanic ethnicity. State partners interviewed patients or their surrogates using the *Listeria* Initiative questionnaire for hypothesis generation (*4*). All three patients reported consuming fresh, soft cheeses before becoming ill; two reported consuming queso fresco, a type of fresh, soft cheese. In this outbreak, a case was defined as an infection in a person with a clinical isolate related within five allele differences by WGS and a specimen collection date from October 20, 2020, to March 17, 2021 (Figure).

Based on food histories from the three index patients, their reported Hispanic ethnicity, and the known association between *L. monocytogenes* and fresh, soft cheeses, CDC asked the Connecticut Department of Public Health (CDPH) to contact the Connecticut patient for brand information. During re-interview, the patient reported consuming brand A queso fresco. CDC conducted a case-case analysis comparing food exposures for four listeriosis patients included in the outbreak (outbreak cases) with completed *Listeria* Initiative questionnaires to exposures for listeriosis patients not associated with an outbreak by WGS from the same states as outbreak cases (control cases). An exact odds ratio analysis was conducted using SAS software (version 9.4; SAS Institute). Consumption of queso fresco (odds ratio [OR] = 51.2; p = 0.002) and other, similar fresh, soft cheeses (OR = 30.4; p<0.001) were both statistically significant. This activity was reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.*

A total of 13 *L. monocytogenes* infections that met the case definition were reported from four states (Connecticut [one], Maryland [five], New York [four], and Virginia [three]). Patients ranged in age from <1 year to 75 years (median = 51 years). All patients reported Hispanic ethnicity; seven were female. Twelve patients were hospitalized; one died. Four patients became ill during pregnancy, resulting in two pregnancy losses and one premature birth; one patient remained pregnant after

* 45 C.F.R. part 46.102(l)(2), 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

becoming ill. Among the eleven patients who completed the *Listeria* Initiative questionnaire, seven reported consuming queso fresco; eight reported consuming other, similar fresh, soft cheeses. Four patients reported consuming brands of cheeses manufactured by firm A, the firm that produces brand A queso fresco.

The Connecticut Food Protection Program and Maryland Rapid Response Team collected samples of fresh, soft cheeses at stores reported by patients, including brand A queso fresco. Connecticut and Maryland collected and tested 61 fresh, soft cheese samples; two yielded *L. monocytogenes*. CDPH identified the outbreak strain of *L. monocytogenes* in two samples of brand A queso fresco. WGS analysis of isolates from the CDPH samples showed they were closely related to the clinical isolates (0–4 allele differences), suggesting that patients became ill from brand A queso fresco. All 13 clinical isolates and two cheese isolates were related within five allele differences by WGS.

Summary

What is already known about this topic?

Listeriosis outbreaks are frequently associated with consumption of queso fresco and other similar fresh, soft cheeses.

What is added by this report?

In early 2021, a multistate outbreak of listeriosis involving 13 cases in four states occurred, resulting in 12 hospitalizations and one death. The outbreak was linked to queso fresco within 19 days of cluster detection. Rapid food testing by regulatory agencies in response to the investigation identified the implicated cheese.

What are the implications for public health practice?

To prevent severe health outcomes among persons at increased risk for listeriosis, public health agencies should improve communications, including implementing new methods of dissemination to emphasize the risk from eating queso fresco and other similar fresh, soft cheeses, even those made with pasteurized milk.

Public Health Response

FDA determined that brand A queso fresco was produced by firm A, located in New Jersey, and initiated an inspection. Firm A produced or handled queso fresco and two similar fresh, soft cheeses (requesón and quesillo) under its own brand name and for private label brands. Firm A agreed to recall brand A queso fresco products with expiration dates from February 26 to March 13, 2021. The initial recall and outbreak investigation were announced on February 19, 2021. Because of cross-contamination concerns, firm A agreed on February 26 to expand the recall to all types of cheese produced or handled in the facility. As a result of this investigation, firm A ceased production, repackaging, and distribution of all products manufactured at the facility.

CDC published seven outbreak notices; FDA posted nine outbreak advisories, two recall notices, and two lists of retail establishments that received recalled product. CDC and FDA communications were available in both English and Spanish. In addition, Connecticut published four public communications. Two patients who became ill after the expanded recall, both with specimen collection dates of March 17, 2021, likely purchased and consumed the queso fresco before the recall given their illness dates and the long incubation period for listeriosis (*5*).

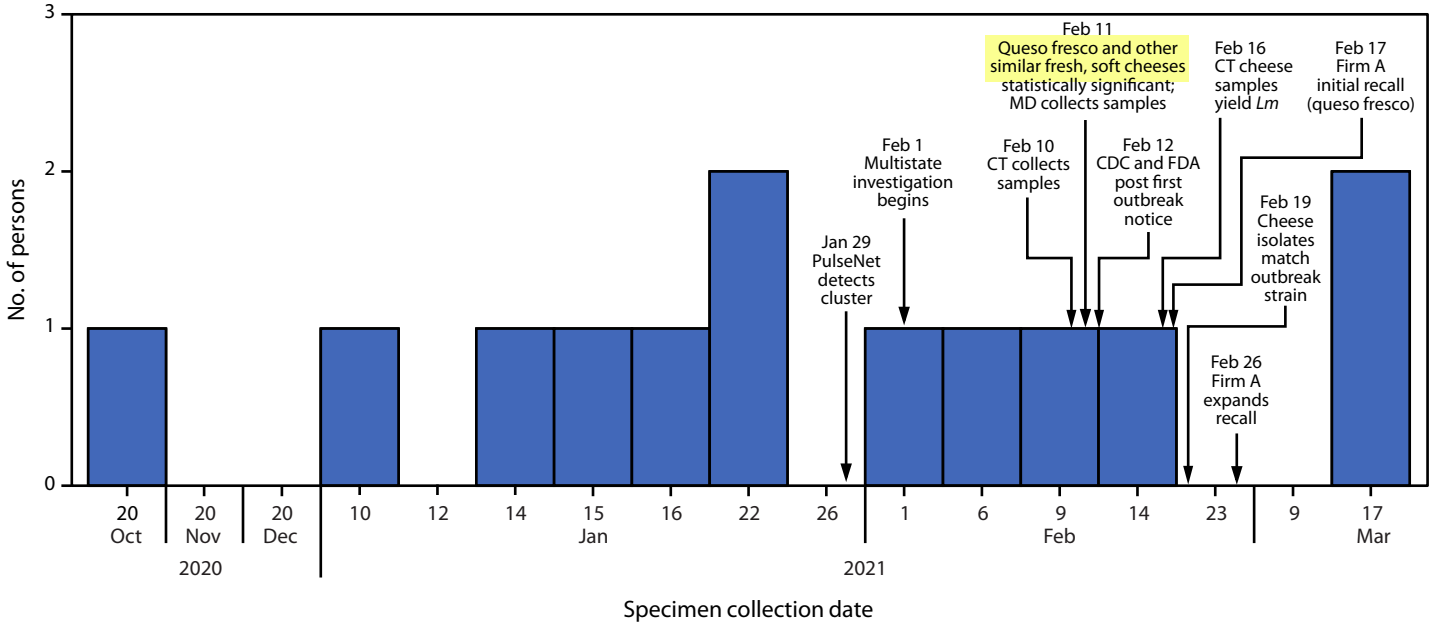
Discussion

Patients in this outbreak were more likely to consume queso fresco and other similar fresh, soft cheeses, compared with patients with sporadic *Listeria* infections reported from the same states. In listeriosis outbreaks, prompt, epidemiologically directed food sampling plays a key role in identifying the source of illness. Without the rapid identification of *L. monocytogenes* in firm A's queso fresco, firm A would not have been identified as the outbreak source as quickly. The public health actions taken within 19 days of cluster identification, firm A's voluntary recalls, and outbreak notices likely prevented additional illnesses or deaths.

In early 2020, during an unrelated outbreak of listeriosis, *Listeria grayi* and *Listeria innocua,* typically nonpathogenic to humans, were found in firm A's processing areas. The presence of *Listeria* species in a processing environment indicates that *L. monocytogenes* could survive in that same environment. FDA issued a warning letter to firm A in 2020 because of violations of Current Good Manufacturing Practice regulations and a lack of hazard analysis and preventive control programs (*6*).

Queso fresco and other similar fresh, soft cheeses made with pasteurized milk continue to constitute a serious risk for listeriosis because cheeses can become contaminated during the production process (after milk pasteurization). High moisture, low salt content, and low acidity support growth of *L. monocytogenes* in these cheeses during refrigerated storage, thereby increasing the risk for illness (*7*). A study of U.S. listeriosis outbreaks associated with soft cheeses during 1998–2014 found that soft cheeses made with pasteurized milk are implicated in more outbreaks than soft cheeses made with unpasteurized milk, which might be related to higher consumption of cheese made with pasteurized milk or to public health messages advising persons at higher risk for listeriosis not to eat cheeses made with unpasteurized milk. Among 17 outbreaks linked to soft cheeses during 1998–2014, eleven were linked to queso fresco and other similar fresh, soft cheeses, three of which included cheeses made with unpasteurized milk. The six outbreaks not linked to these cheeses included sheep's milk, Middle Eastern-style, Eastern European-style, Italian-style, blue-veined, and soft-ripened cheeses (*8*).

FIGURE. Number of persons infected with the outbreak strain of *Listeria monocytogenes*, by date of specimen collection (n = 13) — United States, October 20, 2020–March 17, 2021



Abbreviations: CT = Connecticut; FDA = Food and Drug Administration; *Lm* = *Listeria monocytogenes*; MD = Maryland.

Queso fresco and other similar fresh, soft cheeses, especially those produced in facilities with unhygienic processing conditions, have frequently led to listeriosis outbreaks during the last two decades (*8*). Rapid food testing by regulatory agencies in response to this outbreak investigation identified the implicated cheese. Public health agencies should establish or improve communications, including new methods for disseminating information to emphasize the risk from eating queso fresco and other similar fresh, soft cheeses, even those made with pasteurized milk, to persons at higher risk for listeriosis, including pregnant persons and their newborns, adults aged ≥65 years, and persons with weakened immune systems.

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References

1. CDC. *Listeria* (listeriosis) questions and answers. Atlanta, GA: US Department of Health and Human Services, CDC; 2016. https://www.cdc.gov/listeria/faq.html
2. CDC. PulseNet: whole genome sequencing (WGS). Atlanta, GA: US Department of Health and Human Services, CDC; 2016. https://www.cdc.gov/pulsenet/pathogens/wgs.html
3. Food and Drug Administration. Draft guidance for industry: control of *Listeria monocytogenes* in ready-to-eat foods. Silver Spring, MD: US Department of Health and Human Services, Food and Drug Administration; 2017. https://www.fda.gov/regulatory-information/search-fda-guidance-documents/draft-guidance-industry-control-listeria-monocytogenes-ready-eat-foods
4. CDC. *Listeria* (listeriosis) prevention. Atlanta, GA: US Department of Health and Human Services, CDC; 2019. https://www.cdc.gov/listeria/prevention.html
5. Angelo KM, Jackson KA, Wong KK, Hoekstra RM, Jackson BR. Assessment of the incubation period for invasive listeriosis. Clin Infect Dis 2016;63:1487–9. PMID:27535950 https://doi.org/10.1093/cid/ciw569

6. Food and Drug Administration. FSMA final rule for preventive controls for human food. Silver Spring, MD: US Department of Health and Human Services, Food and Drug Administration; 2020. https://www.fda.gov/food/food-safety-modernization-act-fsma/fsma-final-rule-preventive-controls-human-food
7. Ibarra-Sánchez LA, Van Tassell ML, Miller MJ. Invited review: Hispanic-style cheeses and their association with *Listeria monocytogenes*. J Dairy Sci 2017;100:2421–32. PMID:28189316 https://doi.org/10.3168/jds.2016-12116
8. Jackson KA, Gould LH, Hunter JC, Kucerova Z, Jackson B. Listeriosis outbreaks associated with soft cheeses, United States, 1998–2014. Emerg Infect Dis 2018;24:1116–8. PMID:29774843 https://doi.org/10.3201/eid2406.171051

Post-COVID Conditions Among Adult COVID-19 Survivors Aged 18–64 and ≥65 Years — United States, March 2020–November 2021

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On May 24, 2022, this report was posted as an MMWR *Early Release on the* MMWR *website (https://www.cdc.gov/mmwr).*

A growing number of persons previously infected with SARS-CoV-2, the virus that causes COVID-19, have reported persistent symptoms, or the onset of long-term symptoms, ≥4 weeks after acute COVID-19; these symptoms are commonly referred to as post-COVID conditions, or long COVID (*1*). Electronic health record (EHR) data during March 2020–November 2021, for persons in the United States aged ≥18 years were used to assess the incidence of 26 conditions often attributable to post-COVID (hereafter also referred to as incident conditions) among patients who had received a previous COVID-19 diagnosis (case-patients) compared with the incidence among matched patients without evidence of COVID-19 in the EHR (control patients). The analysis was stratified by two age groups (persons aged 18–64 and ≥65 years). Patients were followed for 30–365 days after the index encounter until one or more incident conditions were observed or through October 31, 2021 (whichever occurred first). Among all patients aged ≥18 years, 38% of case-patients experienced an incident condition compared with 16% of controls; conditions affected multiple systems, and included cardiovascular, pulmonary, hematologic, renal, endocrine, gastrointestinal, musculoskeletal, neurologic, and psychiatric signs and symptoms. By age group, the highest risk ratios (RRs) were for acute pulmonary embolism (RR = 2.1 and 2.2 among persons aged 18–64 and ≥65 years, respectively) and respiratory signs and symptoms (RR = 2.1 in both age groups). Among those aged 18–64 years, 35.4% of case-patients experienced an incident condition compared with 14.6% of controls. Among those aged ≥65 years, 45.4% of case-patients experienced an incident condition compared with 18.5% of controls. These findings translate to one in five COVID-19 survivors aged 18–64 years, and one in four survivors aged ≥65 years experiencing an incident condition that might be attributable to previous COVID-19. Implementation of COVID-19 prevention strategies, as well as routine assessment for post-COVID conditions among persons who survive COVID-19, is critical to reducing the incidence and impact of post-COVID, particularly among adults aged ≥65 years (*2*).

A retrospective matched cohort design was used to analyze EHRs during March 2020–November 2021, from Cerner Real-World Data,* a national, deidentified data set of approximately 63.4 million unique adult records from 110 data contributors in the 50 states. Case-patients (353,164) were adults aged ≥18 years who received either a diagnosis of COVID-19 or a positive SARS-CoV-2 test result† (case-patient index encounter) in an inpatient, emergency department, or outpatient settings within a subset of health care facilities that use Cerner EHRs. Control patients (1,640,776) had a visit in the same month as the matched case-patient (control index encounter) and did not receive a COVID-19 diagnosis or a positive SARS-CoV-2 test result during the observation period. Controls were matched 5:1 with case-patients. All patients included in the analysis were required to have at least one encounter in their EHR during the year preceding and the year after the index encounter.

The occurrence of 26 clinical conditions previously attributed to post-COVID illness was assessed by review of the scientific literature§ (*3*–*5*) (Supplementary Table 1, https://stacks.cdc.gov/view/cdc/117411). Patients were followed for 30–365 days after the index encounter until the first occurrence of an incident condition or until October 31, 2021, whichever occurred first. Case-patients or control patients with a previous history of one of the included conditions in the year before the index encounter were excluded (478,072 patients). The analysis was stratified by age into two groups: adults aged 18–64 and adults aged ≥65 years. Incidence rates per 100 person-months, and RRs with 95% CIs, were calculated. The number of COVID-19 case-patients having

*https://www.cerner.com/solutions/real-world-data?_ga=2.134259058.2081252678.1649198012-1806687702.1649105445

†COVID-19 cases with associated positive test result were identified by the following: Systematized Nomenclature of Medicine (SNOMED) codes 840533007, 840535000, 840539006, and 840546002; *International Classification of Diseases, Tenth Edition, Clinical Modification* (ICD-10-CM) codes B97.29 (March, 2020) and U07.1 (April–May 2020); and Logical Observation Identifiers Names and Codes (LOINC) codes 68993–5, 92142–9, 92141–1, 94309–2, 94307–6, 94308–4, 94500–6, 94502–2, 94533–7, 94534–5, 94559–2, 94756–4, 94757–2, 94758–0, 94845–5, 95406–5, 95409–9, 96091–4, 95425–5, 95423–0, and 96448–6.

§Acute myocardial infarction, cardiac dysrhythmias, cardiovascular disease, heart failure, myocarditis and cardiomyopathy, acute pulmonary embolism, respiratory symptoms, asthma, renal failure, chronic kidney disease, thromboembolic event, cerebrovascular disease, coagulation and hemorrhagic conditions, gastrointestinal and esophageal conditions, neurologic conditions, smell and taste disturbances, mood disorders, other mental conditions, anxiety and fear-related conditions, sleeping disorders, substance-related disorders, malaise and fatigue, muscle disorders, musculoskeletal pain, diabetes type 2, and diabetes type 1.

experienced an incident condition was also estimated by age group.[¶] Nonoverlapping CIs between age groups were considered statistically significant. Analyses were performed using RStudio Workbench (version 3.0; RStudio). This activity was reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.[**]

Among all patients aged ≥18 years, 38.2% of case-patients and 16.0% of controls experienced at least one incident condition (Table). Among persons aged 18–64 years, 35.4% of case-patients and 14.6% of controls experienced at least one incident condition. Among persons aged ≥65 years, 45.4% of case-patients and 18.5% of controls experienced at least one incident condition. The absolute risk difference between the percentage of case-patients and controls who developed an incident condition was 20.8 percentage points for those aged 18–64 years and 26.9 percentage points for those aged ≥65 years. This finding translates to one in five COVID-19 survivors aged 18–64 years and one in four survivors aged ≥65 years experiencing an incident condition that might be attributable to previous COVID-19.

The most common incident conditions in both age groups were respiratory symptoms and musculoskeletal pain (Supplementary Table 2, https://stacks.cdc.gov/view/cdc/117411). Among both age groups, the highest RRs were for incident conditions involving the pulmonary system, including acute pulmonary embolism (RR = 2.2 [patients aged ≥65 years] and 2.1 [patients aged 18–64 years]) and respiratory symptoms (RR = 2.1, both age groups) (Figure). Among patients aged ≥65 years, the risks were higher among case-patients than among controls for all 26 incident conditions, with RRs ranging from 1.2 (substance-related disorder) to 2.2 (acute pulmonary embolism). Among patients aged 18–64 years, the risks were higher among case-patients than among controls for 22 incident conditions, with RRs ranging from 1.1 (anxiety) to 2.1 (acute pulmonary embolism); no significant difference was observed for cerebrovascular disease or mental health conditions, such as mood disorders, other mental conditions, and substance-related disorders.

Differences by age group were noted. The RR for cardiac dysrhythmia was significantly higher among patients aged 18–64 years (RR = 1.7) compared with those aged ≥65 years (1.5). Similarly, the RR for musculoskeletal pain was higher among patients aged 18–64 years (1.6) than among those aged ≥65 years (1.4). Among case-patients, the RRs for 10 incident conditions was significantly higher among those aged ≥65 years than among those aged 18–64 years; these conditions were

[¶] Calculated as the reciprocal of the absolute risk difference of COVID-19 case-patients and non–COVID-19 controls that experience at least one incident condition.

[**] 45 C.F.R. part 46.102(l)(2), 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

TABLE. Percentage of adult COVID-19 case-patients and control patients with ≥1 post-COVID–attributable incident conditions and estimated number of COVID-19 survivors who will experience a post-COVID condition — United States, March 2020–November 2021

Age group, yrs	No. of patients (column %)		No. of patients with ≥1 incident condition (column %*)		Absolute risk difference[†]	No. of COVID-19 survivors with a post-COVID condition[§]
	Case-patients	Control patients	Case-patients	Control patients		
18–64	254,345 (72.0)	1,051,588 (64.1)	90,111 (35.4)	154,011 (14.6)	20.8	1/5
≥65	98,819 (28.0)	589,188 (35.9)	44,840 (45.4)	108,850 (18.5)	26.9	1/4
Total	**353,164 (100)**	**1,640,776 (100)**	**134,951 (38.2)**	**262,861 (16.0)**	**22.2**	**1/4–5**

* Percentage of COVID-19 case-patients or control patients with ≥1 incident condition divided by the total study COVID-19 cohort or control cohort row's age group total.

† Percentage point difference between COVID-19 case-patients and control patients (e.g., the value 20.8 is calculated as 35.4 minus 14.6).

§ Number of COVID-19 survivors who experienced a post-COVID condition estimated as the inverse of the absolute risk difference.

renal failure, thromboembolic events, cerebrovascular disease, type 2 diabetes, muscle disorders, neurologic conditions, and mental health conditions (including mood disorders, anxiety, other mental conditions, and substance-related disorders).

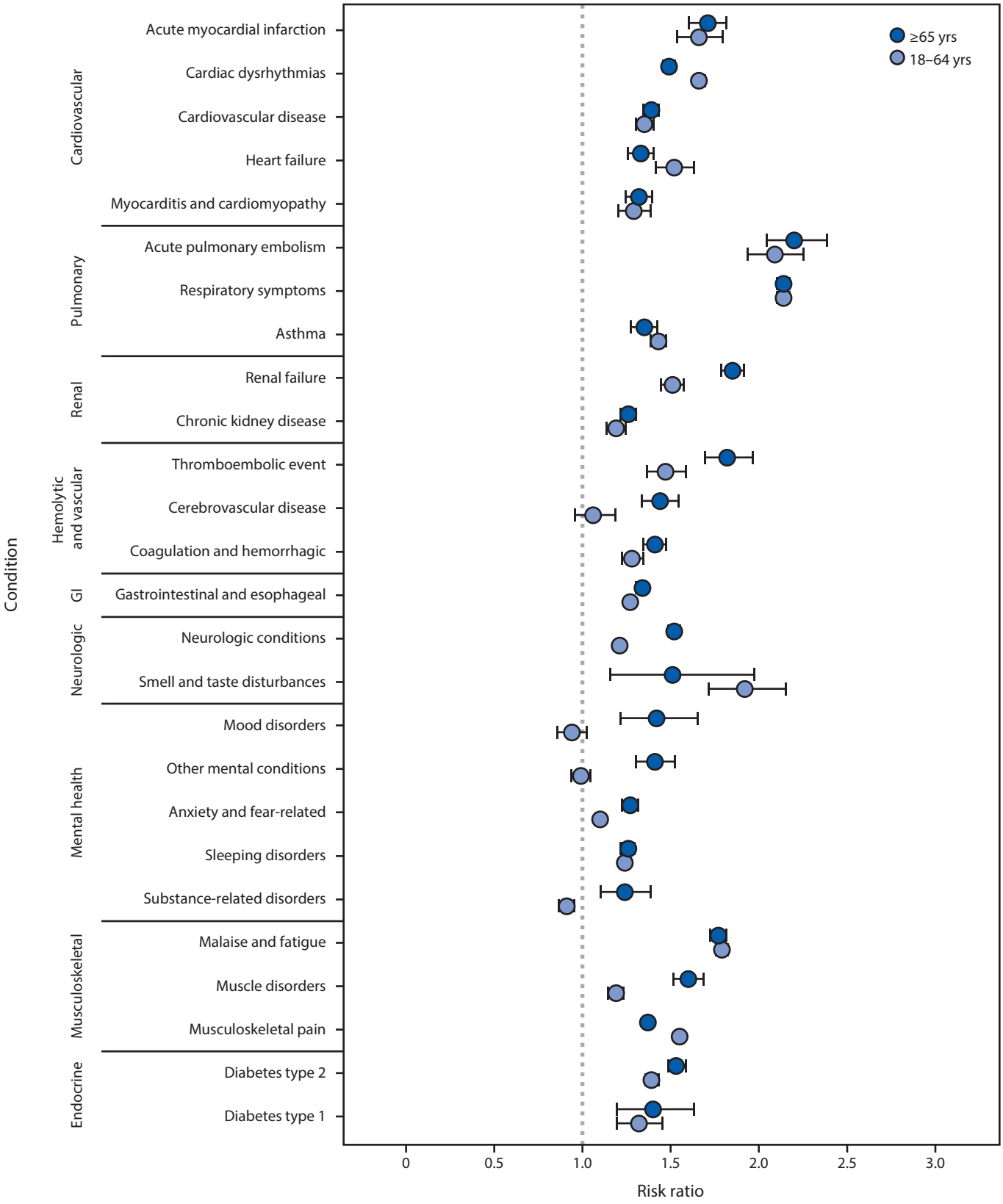
Discussion

The findings from this analysis of a large EHR-based database of U.S. adults indicated that COVID-19 survivors were significantly more likely than were control patients to have incident conditions that might be attributable to previous COVID-19. One in five COVID-19 survivors aged 18–64 years and one in four survivors aged ≥65 years experienced at least one incident condition that might be attributable to previous COVID-19. Independent of age group, the highest RRs were for acute pulmonary embolism and respiratory symptoms.

These findings are consistent with those from several large studies that indicated that post-COVID incident conditions occur in 20%–30% of patients (*6*,*7*), and that a proportion of patients require expanded follow-up care after the initial infection. COVID-19 severity and illness duration can affect patients' health care needs and economic well-being (*8*). The occurrence of incident conditions following infection might also affect a patient's ability to contribute to the workforce and might have economic consequences for survivors and their dependents, particularly among adults aged 18–64 years (*5*). In addition, care requirements might place a strain on health services after acute illness in communities that experience heavy COVID-19 case surges.

COVID-19 survivors aged ≥65 years in this study were at increased risk for neurologic conditions, as well as for four of five mental health conditions (mood disorders, other

FIGURE. Risk ratios* for developing post-COVID conditions among adults aged 18–64 years and ≥65 years — United States, March 2020–November 2021



Abbreviation: GI = gastrointestinal.
* With CIs indicated by error bars; some error bars are not visible because of small CIs.

Summary

What is already known about this topic?

As more persons are exposed to and infected by SARS-CoV-2, reports of patients who experience persistent symptoms or organ dysfunction after acute COVID-19 and develop post-COVID conditions have increased.

What is added by this report?

COVID-19 survivors have twice the risk for developing pulmonary embolism or respiratory conditions; one in five COVID-19 survivors aged 18–64 years and one in four survivors aged ≥65 years experienced at least one incident condition that might be attributable to previous COVID-19.

What are the implications for public health practice?

Implementation of COVID-19 prevention strategies, as well as routine assessment for post-COVID conditions among persons who survive COVID-19, is critical to reducing the incidence and impact of post-COVID conditions, particularly among adults aged ≥65 years.

mental conditions, anxiety, and substance-related disorders). Neurocognitive symptoms have been reported to persist for up to 1 year after acute infection and might persist longer (*9*). Overall, 45.4% of survivors aged ≥65 years in this study had incident conditions. Among adults aged ≥65 years, who are already at higher risk for stroke and neurocognitive impairment, post-COVID conditions affecting the nervous system are of particular concern because these conditions can lead to early entry into supportive services or investment of additional resources into care (*10*).

The findings in this study are subject to at least five limitations. First, patient data were limited to those seen at facilities serviced by Cerner EHR network during January 2020–November 2021; therefore, the findings might not be representative of the entire U.S. adult population or of COVID-19 case patients infected with recent variants. Second, the incidence of new conditions after an acute COVID-19 infection might be biased toward a population that is seeking care, either as a follow-up to a previous complaint (including COVID-19) or for another medical complaint, which might result in a "sicker" control group leading to underestimation of observed risk. Third, COVID-19 vaccination status was not considered in this analysis, nor were potentially confounding factors (e.g., SARS-CoV-2 variant, sex, race, ethnicity, health care entity, or geographic region), because data were not available, were inconsistent, or included a high proportion of missing or unknown values; for example, data were not matched by data contributors, so controls were not necessarily from the same health care entity or region of the country. Differences between the groups might influence the risks associated with survival from COVID-19 and incident conditions, which require further study. Fourth, *International Classification of Disease, Tenth Revision, Clinical Modification* (ICD-10-CM) codes were used to identify COVID-19 case-patients, and misclassification of controls is possible. However, the inclusion of laboratory data to identify case-patients and exclude controls helped to limit the potential for such misclassification. Finally, the study only assessed conditions thought to be attributable to COVID-19 or post-COVID illness, which might have biased RRs away from the null. For example, clinicians might have been more likely to document possible post-COVID conditions among case-patients. In addition, because several conditions examined are also risk factors for moderate to severe COVID-19, it is possible that case-patients were more likely to have had an existing condition that was not documented in their EHR during the year preceding their COVID-19 diagnosis, resulting in overestimated risk for this group.

As the cumulative number of persons ever having been infected with SARS-CoV-2 increases, the number of survivors suffering post-COVID conditions is also likely to increase. Therefore, implementation of COVID-19 prevention strategies, as well as routine assessment for post-COVID conditions among persons who survive COVID-19, is critical to reducing the incidence and impact of post-COVID conditions, particularly among adults aged ≥65 years (*2*). These findings can increase awareness for post-COVID conditions and improve post-acute care and management of patients after illness. Further investigation is warranted to understand the pathophysiologic mechanisms associated with increased risk for post-COVID conditions, including by age and type of condition.

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References

1. CDC. Long COVID or post-COVID conditions. Atlanta, GA: US Department of Health and Human Services, CDC; 2022. Accessed April 22, 2022. https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html
2. Antonelli M, Penfold RS, Merino J, et al. Risk factors and disease profile of post-vaccination SARS-CoV-2 infection in UK users of the COVID Symptom Study app: a prospective, community-based, nested, case-control study. Lancet Infect Dis 2022;22:43-55. PMID:34480857 https://doi.org/10.1016/S1473-3099(21)00460-6
3. Al-Aly Z, Xie Y, Bowe B. High-dimensional characterization of post-acute sequelae of COVID-19. Nature 2021;594:259–64. PMID:33887749 https://doi.org/10.1038/s41586-021-03553-9
4. Cohen K, Ren S, Heath K, et al. Risk of persistent and new clinical sequelae among adults aged 65 years and older during the post-acute phase of SARS-CoV-2 infection: retrospective cohort study. BMJ 2022;376:e068414. PMID:35140117 https://doi.org/10.1136/bmj-2021-068414

5. Rajan S, Khunti K, Alwan N, et al. In the wake of the pandemic: preparing for long COVID. Copenhagen, Denmark: European Observatory on Health Systems and Policies; 2021. PMID:33877759
6. Ayoubkhani D, Khunti K, Nafilyan V, et al. Post-COVID syndrome in individuals admitted to hospital with COVID-19: retrospective cohort study. BMJ 2021;372:n693. PMID:33789877 https://doi.org/10.1136/bmj.n693
7. Donnelly JP, Wang XQ, Iwashyna TJ, Prescott HC. Readmission and death after initial hospital discharge among patients with COVID-19 in a large multihospital system. JAMA 2021;325:304–6. PMID:33315057 https://doi.org/10.1001/jama.2020.21465
8. CDC. Science brief: indicators for monitoring COVID-19 community levels and making public health recommendations. Atlanta, GA: US Department of Health and Human Services; 2022. https://www.cdc.gov/coronavirus/2019-ncov/science/science-briefs/indicators-monitoring-community-levels.html
9. Mueller AL, McNamara MS, Sinclair DA. Why does COVID-19 disproportionately affect older people? Aging (Albany NY) 2020;12:9959–81. PMID:32470948 https://doi.org/10.18632/aging.103344
10. Mohamed MS, Johansson A, Jonsson J, Schiöth HB. Dissecting the molecular mechanisms surrounding post-COVID-19 syndrome and neurological features. Int J Mol Sci 2022;23:4275. PMID:35457093 https://doi.org/10.3390/ijms23084275

Notes from the Field

Self-Reported Health Symptoms Following Petroleum Contamination of a Drinking Water System — Oahu, Hawaii, November 2021–February 2022

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In late November 2021, the Hawaii Department of Health (HDOH) received reports from Oahu residents of a fuel-like odor coming from their drinking water (*1*), which was later determined to be related to a November 20, 2021, petroleum (jet fuel) leak at the Red Hill Bulk Fuel Storage Facility. The petroleum leak contaminated the Joint Base Pearl Harbor-Hickam water system,* which supplies an estimated 9,694 civilian and military households (*2*), in addition to schools and workplaces. HDOH issued a drinking water advisory on November 30, 2021 (*1*), which was not lifted for all affected zones until March 18, 2022.† Persons in thousands of households were offered temporary housing, and alternative drinking water was provided to users of affected water. HDOH requested epidemiologic assistance (Epi-Aid) from CDC/Agency for Toxic Substances and Disease Registry (ATSDR) to assess the incident's impact on civilian health in the affected area; this was later expanded to include military-affiliated persons.

The team adapted an interviewer-administered survey from the ATSDR Assessment of Chemical Exposures (ACE) toolkit to collect information about potential exposure to contaminated water, health symptoms experienced, and medical care sought. The survey was modified to be self-administered online, similar to a previous ACE investigation (*3*). Persons present in the affected area after the incident were eligible to complete the survey during January 7–February 10, 2022. Parents and guardians completed the survey on behalf of persons aged <18 years. The survey was promoted through electronic and in-person outreach. Household-level response rates were calculated using ArcGIS Pro and U.S. Navy data (*3*). Descriptive statistics were calculated using R software (version 4.1.1; R Foundation). This activity was reviewed by CDC and was conducted consistent with applicable federal law and CDC policy.§

A total of 2,289 eligible participants submitted surveys, with at least one household member participating from 1,389 (14%) of 9,694 estimated affected households. The median participant age was 33 years (range = 1–84 years). Participants were predominantly female (59%), non-Hispanic (81%), military-affiliated (88%), and identified their race as White (74%). Among all participants who were residents in the affected area, 1,115 (52%) reported at least one indication that their water was contaminated (i.e., petroleum smell or taste, or visible oily sheen). Participants indicated that they ingested the potentially contaminated water through oral hygiene (1,821; 80%), drinking (1,650; 72%), and cooking (1,629; 71%). Most participants (2,123; 93%) switched to an alternative water source after learning of the incident.

Most participants reported experiencing one or more new or worsened symptoms after the incident (1,980; 87%), many of whom reported symptoms lasting ≥30 days (1,493; 75%). The largest percentages of reported symptoms were those related to the nervous system (62%), followed by the gastrointestinal system (58%), skin (58%), ear, nose, and throat (47%), mental health (46%), eyes (42%), and respiratory system (31%) (Table). Medical care was sought by 853 (37%) of participants after the incident, including 17 who were hospitalized overnight. Among symptomatic participants, 1,591 of 1,980 symptomatic participants (80%) reported improvement in symptoms after switching to an alternative water source. In an open-text field, 53 (2%) participants expressed concerns about possible long-term health effects.

This novel incident of jet fuel–contaminated drinking water disrupted the lives of thousands of persons. An online survey paired with robust in-person and electronic promotion facilitated rapid information collection from many affected persons across a wide geographic area, including many who were displaced from their homes. This survey method did not allow for prevalence estimates, nor did it capture the full scope of health impacts. Reported symptoms, such as those related to the respiratory system, gastrointestinal tract, nervous system, and mental health, were consistent with previous studies of exposure to petroleum hydrocarbons¶ (*4,5*), and accounts of some relief from symptoms after switching to an alternative

* https://www.cpf.navy.mil/News/Article/2870459/opening-statements-at-hawaii-state-legislature-briefing/msclkid/opening-statements-at-hawaii-state-legislature-briefing/

† https://health.hawaii.gov/news/newsroom/doh-declares-four-navy-drinking-water-distribution-system-zones-safe/

§ 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

¶ https://wwwn.cdc.gov/TSP/ToxFAQs/ToxFAQsDetails.aspx?faqid=772&toxid=150

TABLE. Occurrence of new or worsened symptoms, and symptoms persisting for ≥30 days after the contamination of a water system by a petroleum leak on November 20, 2021, self-reported by participants of the Hawaii Assessment of Chemical Exposures survey (N = 2,289) — Oahu, Hawaii, November 2021–February 2022

Self-reported symptom	No. (%) of survey participants	
	Experiencing new or worsened symptoms	Experiencing symptoms for ≥30 days*
Eyes	**967 (42)**	**514/967 (53)**
Increased tearing	498 (22)	303/498 (61)
Irritation/Pain/Burning of eyes	879 (38)	453/879 (52)
Ear, nose, and throat	1,078 (47)	553/1,078 (51)
Runny nose	715 (31)	388/715 (54)
Nose bleeds	191 (8)	86/191 (45)
Burning nose or throat	739 (32)	87/739 (12)
Ringing in ears	405 (18)	263/405 (65)
Nervous system	**1,428 (62)**	**959/1,428 (67)**
Headache	1,318 (58)	726/1,318 (55)
Dizziness/Lightheadedness	875 (38)	463/875 (53)
Seizures/Convulsions	23 (1)	18/23 (78)
Feeling fatigued	1,016 (44)	696/1,016 (69)
Loss of consciousness/Fainting	52 (2)	29/52 (56)
Confusion	424 (19)	271/424 (64)
Difficulty concentrating	738 (32)	530/738 (72)
Difficulty remembering things	644 (28)	483/644 (75)
Respiratory/Cardiovascular	**719 (31)**	**463/719 (64)**
Chest tightness or pain/Angina	362 (16)	206/362 (57)
Wheezing in chest	189 (8)	126/189 (67)
Difficulty breathing/Feeling out-of-breath	416 (18)	271/416 (65)
Coughing	522 (23)	303/522 (58)
Burning lungs	185 (8)	107/185 (58)
Gastrointestinal	**1,332 (58)**	**566/1,332 (43)**
Nausea	929 (41)	391/929 (42)
Vomiting	370 (16)	100/370 (27)
Diarrhea	1,121 (49)	397/1,121 (35)
Dermatologic	**1,322 (58)**	**880/1,322 (67)**
Irritation/Pain/Burning of skin	859 (38)	476/859 (55)
Skin rash	925 (40)	506/925 (55)
Skin blisters	169 (7)	101/169 (60)
Dry or itchy skin	1,144 (50)	771/1,144 (67)
Mental health	**1,049 (46)**	**865/1,049 (83)**
Anxiety	839 (37)	667/839 (80)
Agitation/Irritability	696 (30)	549/696 (79)
Difficulty sleeping	744 (33)	590/744 (79)
Feeling depressed	463 (20)	364/463 (79)
Paranoia	226 (10)	179/226 (79)
Tension/Nervousness	656 (29)	524/656 (80)
Other†	**360 (16)**	**236/360 (66)**

* Among those who reported experiencing symptom.
† Participants could report up to four additional symptoms not listed in the symptoms section of the survey.

water source support exposure-related health effects. These results highlight the need for preventing exposure to petroleum products and might aid public health professionals and clinicians in detecting and responding to future similar incidents. Exposure levels, duration, and long-term health effects, however, are uncertain. Additional follow-up of the affected population might improve understanding of the overall health impact of this and other petroleum exposure incidents.

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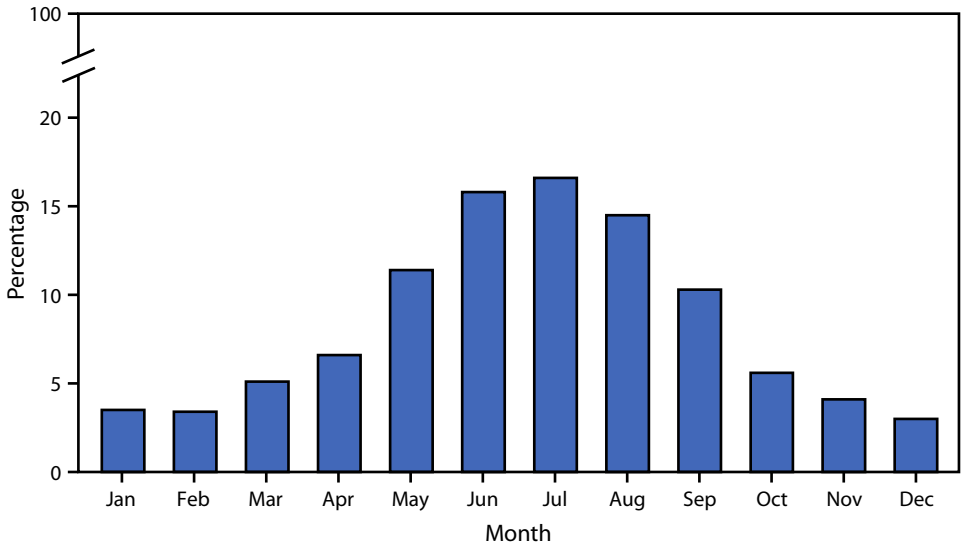
References

1. Hawaii Department of Health. Hawai'i Department of Health advises Navy water system consumers not to drink, consume tap water (Press release). Honolulu, HI: Hawaii Department of Health; November 30, 2021. https://health.hawaii.gov/news/newsroom/hawaii-department-of-health-advises-navy-water-system-consumers-not-to-drink-consume-tap-water/
2. Joint Base Pearl Harbor-Hickam Interagency Drinking Water System Team. Water system flushing zone map. Oahu, HI. Accessed March 14, 2022. https://www.cpf.navy.mil/Portals/52/Downloads/JBPHH-Water-Updates/20220130_Flushing_Map_Status.pdf?ver=z8TDJP-ippC8g5Qg9j3RKg%3d%3d
3. Surasi K, Nakayama JY, Johnson M, et al. Notes from the field: deployment of an electronic self-administered survey to assess human health effects of an industrial chemical facility fire—Winnebago County, Illinois, June–July 2021. MMWR Morb Mortal Wkly Rep 2021;70:1715–6. PMID:34882658 https://doi.org/10.15585/mmwr.mm7049a4
4. Bendtsen KM, Bengtsen E, Saber AT, Vogel U. A review of health effects associated with exposure to jet engine emissions in and around airports. Environ Health 2021;20:10–20. PMID:33549096 https://doi.org/10.1186/s12940-020-00690-y
5. D'Andrea MA, Reddy GK. The development of long-term adverse health effects in oil spill cleanup workers of the Deepwater Horizon offshore drilling rig disaster. Front Public Health 2018;6:117. PMID:29755965 https://doi.org/10.3389/fpubh.2018.00117

QuickStats

FROM THE NATIONAL CENTER FOR HEALTH STATISTICS

Percentage Distribution of Deaths Involving Injuries from Recreational and Nonrecreational Use of Watercraft,* by Month — United States, 2018–2020



* Deaths were identified using *International Classification of Diseases, Tenth Revision* underlying cause of death codes V90–V94 (water transport) for a total of 1,508 deaths during 2018–2020. Water transport includes recreational and nonrecreational use of motorized (e.g., merchant ship, ferry, passenger ship, fishing boat, and jet ski) and nonmotorized (e.g., canoe, kayak, inflatable craft, surfboard, and windsurfer) watercraft. Deaths resulted from drowning, submersion, and other types of injuries. All water transport deaths were unintentional.

During 2018–2020, 1,508 deaths occurred involving injuries from recreational and nonrecreational use of watercraft. The percentage of deaths each month ranged from 3.0% in December to 16.6% in July. Most deaths (68.6%) occurred during May–September.

Source: National Vital Statistics System, Mortality Data. https://www.cdc.gov/nchs/nvss/deaths.htm

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