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Brief Report

Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis



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ARTICLE INFO

Article history:

Received 21 May 2020

Received in revised form

22 May 2020

Accepted 22 May 2020

Keywords:

Intellectual disability

Developmental disability

Coronavirus

COVID-19

ABSTRACT

Background: Despite possibly higher risk of severe outcomes from COVID-19 among people with intellectual and developmental disabilities (IDD), there has been limited reporting of COVID-19 trends for this population.

Objective: To compare COVID-19 trends among people with and without IDD, overall and stratified by age.

Methods: Data from the TriNetX COVID-19 Research Network platform was used to identify COVID-19 patients. Analysis focused on trends in comorbidities, number of cases, number of deaths, and case-fatality rate among patients with and without IDD who had a positive diagnosis for COVID-19 through May 14, 2020.

Results: People with IDD had higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes. Distinct age-related differences in COVID-19 trends were present among those with IDD, with a higher concentration of COVID-19 cases at younger ages. In addition, while the overall case-fatality rate was similar for those with IDD (5.1%) and without IDD (5.4%), these rates differed by age: ages ≤ 17 – IDD 1.6%, without IDD $< 0.01\%$; ages 18–74 – IDD 4.5%, without IDD 2.7%; ages ≥ 75 – IDD 21.1%, without IDD, 20.7%.

Conclusions: Though of concern for all individuals, COVID-19 appears to present a greater risk to people with IDD, especially at younger ages. Future research should seek to document COVID-19 trends among people with IDD, with particular attention to age related trends.

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Introduction

People with intellectual and developmental disability (IDD) are a vulnerable health population that does not receive adequate attention within public health research and intervention/efforts.^{1,2} An estimated 2.6 to 4 million people within the noninstitutionalized United States (US) population have an intellectual or developmental disability (IDD).^{3,4} In the US, developmental disabilities typically include more common disabilities such as intellectual disability, cerebral palsy, and Down syndrome, in addition to more rare developmental disabilities, such as fragile X and Prader-Willi syndromes.⁵ Previous studies have identified that people with

IDD have higher prevalence of specific co-morbidities, such as hypertension, heart disease, respiratory disease, and diabetes,⁶ which are identified as risk factors for poor outcomes from COVID-19.^{7,8}

To date, there appear to be only three reports of COVID-19 death trends among individuals with IDD. An article in the New York Times⁹ details that as of April 6, 2020, the COVID-19 death rate among adults with IDD receiving residential services in the state of New York was 9.5%,⁹ compared to a substantially lower overall death rate from COVID-19 in New York State at 4.0%.¹⁰ Two reports from European countries indicate similar to lower death rates among people with IDD. Utilizing an online database that registers COVID-19 cases among people with IDD in the Netherlands, an Academic Collaborative at Radboud University Medical Center in Nijmegen¹¹ report a 13% death rate as of May 15, 2020, compared to the overall COVID death rate in the Netherlands at 12.9%.¹² As of May 11, 2020, the Swedish National Board of Health and Welfare

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reports a death rate of 7.7% among individuals with IDD receiving governmental housing support,¹² compared to an overall COVID death rate in Sweden of 12.7%.¹³

This paucity of data on COVID-19 trends among the IDD population further exposes the reality that there is no adequate surveillance structure in place to monitor COVID-19, or other public health outcomes, among the IDD population.¹⁴ This is even more disconcerting during this time in which populations with higher prevalence of identified co-morbidities, such as people with IDD, may be at increased risk of developing severe outcomes, including death, from COVID-19.^{15,16} While this overarching flaw in the public health structure cannot be remedied at this time, it is appropriate to utilize all available administrative data, especially data inclusive of ICD-10 diagnoses codes, on individuals with IDD¹⁷ in order to better understand the effects of COVID-19. Therefore, utilizing a real-time database of electronic medical records, TriNetX, we compared COVID-19 death rates and co-morbidities between individuals with and without IDD, overall and by age group. Our hypotheses were that 1) people with IDD would have higher prevalence of pre-existing conditions associated with higher COVID-19 morbidity and mortality outcomes, and 2) the COVID-19 case-fatality rate would be higher for individuals with than without IDD individuals with IDD.

Methods

Data for this study were obtained from the TriNetX COVID-19 Research Network platform, a global federated network of electronic medical record (EMR) data from 42 health care organizations representing hospitals, primary care, and specialty treatment providers designed to facilitate research related to COVID-19. Health care organizations contributing EMR data to the TriNetX platform are typically large academic health centers and their affiliates. TriNetX provides access to continuously updated, de-identified aggregate EMR data including demographics, diagnoses, procedures, medications, laboratory values, and genomics. At the time of the current study, the network included data from approximately 55 million patients. The TriNetX platform is described in detail elsewhere.^{18,19}

The current study included EMR data on all COVID-19 patients included in the TriNetX COVID-19 Research Network as of May 14, 2020. COVID-19 patients were defined as those with either a COVID-19 diagnosis code (ICD-10 codes: B34.2, B97.29, J12.81, U07.1, U07.2) or a positive SARS-CoV-2 laboratory test result (LOINC codes: 94500-6, 94315-9, 94309-2, 94533-7, 94534-5, 94559-2) since January 20, 2020. We excluded patients with diagnosis codes of other specified viral infection (ICD-9 code: 097.89) or suspected exposure to other biologic agents (ICD-10 code: Z03.818) during the same timeframe. Patients were then categorized as those with and without diagnosed developmental disability based on ICD-10 codes, including intellectual disability (F70-79), cerebral palsy (G80), Down syndrome (Q90), and other developmental disabilities (F80-89, Q91-99).

Descriptive statistics of demographic characteristics (age, sex, race, ethnicity, and geographic region) and documentation of co-morbidities related to risk for severe outcomes with COVID-19 up to the date of the first COVID-19 documentation in the EMR (diseases of the respiratory system – ICD-10 codes: J00-99; endocrine, nutritional and metabolic diseases – ICD-10 codes: E00-89; diseases of the circulatory system – ICD-10 codes: I00-99) were compared between the COVID-19 patients with and without diagnosed intellectual or developmental disability. Trends in number of cases, number of deaths, and case-fatality rates were then compared between groups. Age distributions for number of cases and number of deaths were computed for both patient groups.

Deaths occurring within 30 days of the date of first COVID-19 documentation in the EMR were identified and used to calculate case-fatality rates and 95% confidence intervals. Age groups were selected based upon the knowledge that COVID-19 rates are substantially lower among children,¹⁶ and that a disproportionately lower percent of adults with IDD live into older age.²⁰ All statistical analyses were conducted on the TriNetX platform, which utilizes a combination of JAVA™, R,²¹ and Python™ programming languages.

Results

Patient characteristics

We identified 30,282 patients who met the COVID-19 inclusion and exclusion criteria, including 474 patients with and 29,808 patients without a developmental disability indicated in their record. Among the patients with a diagnosis of developmental disability, 33% had an intellectual disability (F70-79), 56% had a pervasive and specific developmental disorder (F80-89), 18% had cerebral palsy (G80), and 21% had a chromosomal abnormality (Q90-99), including 5% with Down syndrome (Q90).

A comparison of demographic characteristics and co-morbidities between patients with and without IDD, stratified by age group, is presented in Table 1. Biological sex distributions for patients with and without IDD were similar for those 17 years of age or younger and those 18–74. However, for those age 75 and over, a greater percentage of the IDD sample was female. For those age 18 and over, a greater percentage of patients with IDD were identified as White, however, there is an inordinate percentage of patients without IDD identified race as ‘Unknown.’ For the two age groups in which geographic comparisons were possible, those ages 0–17 and those ages 18–74, a greater percentage of patients without IDD were from countries outside of the US.

Rates of co-morbidities were noticeably higher for patients with IDD than without IDD for all age groups, but varied by type of disease. Rates of co-morbid respiratory diseases were 19–21% points higher, and endocrine, nutritional, or metabolic disorders were 34–41% points higher for patients with IDD across age groups. Rates of co-morbid diseases of the circulatory system were also higher for patients with IDD across all age groups, but with a gradual decrease in the difference with age: 35% points higher at ages 0–17; 33% points higher at ages 18–74; and 27% points higher at ages 75 and older.

Case distribution and fatality rate

A comparison of the age distribution of overall cases, deaths, and the case fatality rate between patients with and without IDD is presented in Table 2. The age distribution of cases and deaths was distinctly different for patients with and without IDD. While the percentage of overall cases peaked for patients with IDD (65.6%) and without IDD (82%) at ages 18–74, it was remarkably higher for patients with IDD (26.4%) than without IDD (2.7%) at ages 0–17, and remarkably lower for patients with IDD (8%) than without IDD (15.3%) at ages 75 and over. Consistent with prior evidence from the general population, among patients without IDD, the percentage of overall deaths increased with age, peaking at 58.4% at ages 75 and over. In comparison, although the peak percentage was almost identical for patients with IDD, 58.3%, it occurred at ages 18–74.

The overall case-fatality rate was comparable for patients with IDD (5.1%) and without IDD (5.4%). Yet, this consistency in the overall rate conceals important age-related similarities and differences between the two groups. The case-fatality rate among patients age 75 and over was similar for patients with IDD (21.1%) and without IDD (20.7%). However, the COVID-19 case-fatality rate was

Table 1
Characteristics of patients with COVID-19 by intellectual and developmental disability (IDD) status, stratified by age group.

Characteristic	Age 0–17		Age 18–74		Age 75 and over	
	IDD, N = 125	No IDD, N = 791	IDD, N = 311	No IDD, N = 24,456	DD, N = 38	No IDD, N = 4,561
Mean Age (SD)	7.9 (5.9)	7.0 (6.4)	46.8 (16.7)	47.4 (14.5)	82.5 (5.8)	83.1 (5.1)
	(%)	(%)	(%)	(%)	(%)	(%)
Sex						
Male	54	52	48	44	37	47
Female	46	47	52	56	63	53
Race						
White	39	36	60	34	68	39
Black or African-American	14	15	21	19	^a	14
Other	5	3	1	3	^a	2
Unknown	42	46	18	44	^a	45
Ethnicity						
Hispanic	14	16	6	8	6	2
Non-Hispanic	24	20	47	30	47	22
Unknown	62	64	47	61	47	76
Geography						
Northeast	37	28	28	23	^a	24
Southeast	14	7	30	15	^a	10
Midwest	33	26	15	18	^a	18
West	8	17	17	16	^a	8
Outside US	8	21	10	29	^a	41
Co-morbidities						
Diseases of the Respiratory System (J00–99)	90	71	89	68	92	73
Endocrine, Nutritional and Metabolic Diseases (E00–89)	56	20	84	43	95	61
Diseases of the Circulatory System (I00–99)	45	10	69	36	95	68

^a Could not be determined for privacy reasons.

higher for patients with IDD at younger ages. For patients age 0–17, the case-fatality rate was 1.6% among patients with IDD and <0.1% among patients without IDD. For those ages 18–74, the case-fatality rate was 4.5% among patients with IDD and 2.7% among patients without IDD.

Discussion

In this analysis of the TriNetX data during this pandemic, we partially confirm our hypotheses. People with a positive diagnosis for COVID-19, who also had an IDD diagnosis, demonstrated higher rates for all pre-existing conditions associated with COVID-19 disease severity and mortality (circulatory, endocrine, pulmonary), across all age groups. Although overall case-fatality rates were similar for those with (5.1%) and without (5.4%) IDD, people with IDD had higher case-fatality rates within the 18–74 years age range (4.5%) compared to those without IDD (2.7%), and also in the 0–17 years age group, but not among those 75 years and older. Though not testable with the current data, results from this study point to two mechanisms that may inform differences in COVID-19 death rates between people with and without IDD and should be explored in future research: 1) differences in the co-morbidity rates between those with and without IDD that was observed in this study; 2) a possible heterogeneity of frailty effect, with a disproportionate percentage of adults with IDD dying at younger ages resulting in

similar morbidity and mortality outcomes for adults with and without IDD at older ages.^{20,22}

Results from this study highlight the importance of accounting for age related differences in COVID-19 death rates. The prior reports of higher COVID-19 death rates for people with IDD reported by the New York Times, and lower to similar death rates in Sweden and the Netherlands, respectively, do not detail rates by age group. Thus, it is difficult to compare our results to these reports. Yet, it is important to note that case-fatality rates in this study were similar for people with and without IDD when not accounting for age, but considerably different when accounting for age. In addition, comparisons between reports are not advisable due to differences in governmental responses between countries, and differences in the types of samples (i.e. the New York Times report only included individuals with IDD living in congregate settings).

Strengths and limitations

We utilized a novel assessment COVID-19 trends for people with and without IDD using real-time EMR data from the TriNetX COVID-19 Research Network platform. This report appears to be the earliest empirical evidence of differences in case-fatality rates for people with and without IDD by age, providing a baseline point of comparison for future research on this topic.

Despite this contribution to our understanding of COVID-19

Table 2
Case fatality rate within 30 days for patients with COVID-19 with and without intellectual and developmental disability (IDD), overall and stratified by age.

	IDD			No IDD		
	No. of cases (% of total)	No. of deaths (% of total)	Case-fatality rate % (95% CI)	No. of cases (% of total)	No. of deaths (% of total)	Case-fatality rate % (95% CI)
All	474	24	5.1 (3.4, 7.4)	29,808	1614	5.4 (5.2, 5.7)
0–17	125 (26.4)	2 (8.3)	1.6 (0.4, 5.6)	791 (2.7)	1 (<.01)	0.1 (0.0, 0.7)
18–74	311 (65.6)	14 (58.3)	4.5 (2.7, 7.4)	24,456 (82.0)	671 (41.6)	2.7 (2.5, 3.0)
75 and over	38 (8.0)	8 (33.3)	21.1 (11.1, 36.3)	4,561 (15.3)	942 (58.4)	20.7 (19.5, 21.9)

Note: Case fatality rate = No. of deaths/No. of cases.

trends among people with IDD, there are a number of data limitations to the current study. As with the majority of studies that utilize health records to analyze IDD trends, the TriNetX data includes a small number of IDD cases, limiting our ability to further specify age groups. In addition, the TriNetX platform does not represent the general population, but rather represents only those people who seek medical care within the 42 health care organizations in the network. Within the database for this report, there is a much larger representation from the US especially for people with IDD; within the US, more cases are from systems in the Northeast and Midwest. We are also unable to control for any confounding effects which could influence risk for death. To minimize that effect, we did stratify by age. There are always possible inaccuracies within EMR data related to coding or data entry errors. Because of the statistical analyses built into the platform, we were limited in our choice of variables and statistical tests. We were unable to clearly establish deaths documented as being specifically related to COVID-19, and thus we determined death as documentation up to 30 days post diagnosis of COVID-19 to minimize deaths related to other causes, but possibly missing COVID-19 related deaths outside this time frame. In addition, the TriNetX platform does not allow for statistical testing of differences in demographic and co-morbidity characteristics.

Despite these limitations, this exploratory analysis of COVID-19 trends among people with and without IDD does provide evidence of a possibly different risk and outcome trajectories.

Conclusions

Results from this study confirm that people with IDD have higher prevalence of comorbid risk factors (i.e. hypertension, heart disease, respiratory disease, and diabetes) often associated with poorer COVID-19 outcomes.¹² While not testable with the data utilized in this study, this finding suggests that people with IDD may be at higher risk of developing more severe outcomes from COVID-19, including death. Results from this study also point to distinct age-related differences in COVID-19 trends among people with and without IDD. The age-related distribution of COVID-19 cases peaked for both groups at ages 18–74, but was comparatively higher for those with IDD at ages 0–17, and comparatively lower at ages 75 and over. In addition, the age-related distribution of COVID-19 deaths peaked earlier, at ages 18–74, for those with IDD, compared to ages 75 and older for those without IDD. Further emphasizing age related differences, people with IDD had a comparatively higher case-fatality rate than those without IDD at ages 0–17 and 18–74, but a similar case-fatality rate at ages 75 and over. Future work must continue to monitor COVID-19 trends among this and other disability groups with all available data sources, paying particular attention to age related trends when possible.

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