

COMMENTARY

The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States

Jonathan Gleason, MD, Wendy Ross, MD, Alexander Fossi, MPHc, Heather Blonsky, MAS, Jane Tobias, DNP, RN, MSN, CPNP-PC, Mary Stephens, MD

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A cross-sectional study of 64,858,460 patients across 547 health care organizations reveals that having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality. Screening for Covid-19, care coordination, and vaccination efforts should be intense within this population that is less able to consistently use masks and socially distance.

Individuals with intellectual disabilities have poor health outcomes.^{1,2} Life expectancy for this population and those with developmental disabilities is nearly 20 years below that of the general population, and mortality for those with intellectual disabilities is significantly higher across their lifespan.³ Increased mortality in those with intellectual disabilities is caused by a number of factors and the impact of each is not well explored; in some cases, the cause of their disability or complications associated with their disability (in particular, difficulties with aspiration) may contribute to higher risk of mortality.⁴ In other cases, socioeconomic factors, obstacles to receiving the full amount of health care to which they should be entitled, and obstacles to effective advocacy for this population may contribute to an inability to receive appropriate and effective health care, which in turn leads to increased morbidity and mortality.³

Several smaller studies have demonstrated the effects of the pandemic on those with intellectual disabilities. One report demonstrated a higher case fatality rate for individuals with intellectual disabilities in California (.055 compared with .019 among the general population).⁵ A similar study of New York State residents found that those with intellectual disabilities or developmental disabilities were at greater risk of mortality, with those in residential group homes at especially high risk owing largely to elevated case rates. In this study, the mortality of those with intellectual

disabilities and developmental disabilities was nearly 8 times higher than the general population, illustrating the severity of the risk that this population faces.⁶ The largest study of intellectual disability and Covid-19 outcomes examined claims data from 467,773 patients who received Covid-19 diagnoses between April and August of 2020. This study found that those with developmental disabilities were over 3 times as likely to die following a diagnosis of Covid-19 and that those with intellectual disabilities were 2.75 times as likely to die following such a diagnosis.⁷

While it is clear that individuals with intellectual disabilities are at higher risk for dying from Covid-19, the full impact of Covid-19 on individuals with intellectual disabilities across the United States remains unclear. The current study utilizes a large national sample of patients to describe the relative impact of Covid-19 on individuals with intellectual disabilities versus the general population. We hypothesize that individuals with intellectual disabilities are at significantly elevated risk of contracting Covid-19 and that they will subsequently be admitted to ICUs and/or die in-hospital more often.

Methodology

This is a cross-sectional study across 547 health care organizations in the United States from January 2019 through November 2020 using the Vizient Clinical Database/Resource Manager (CDB/RM). The CDB/RM includes patient data from an analytic platform for performance improvement populated by hundreds of health systems and community hospitals nationwide, including nearly all academic medical centers. Covid-19 was identified by a principal or secondary diagnosis code of U07.1 starting in April 2020, or in March 2020 with either a principal diagnosis of B97.29, or a secondary diagnosis of B97.29 with a principal diagnosis of J12.98 or J12.9 (viral pneumonia), or a diagnosis-related group in the following list, representing respiratory diseases, infections, and sepsis: 177, 178, 179, 207, 208, 853, 854, 855, 870, 871, or 872.

“*Covid-19 has had a devastating impact on individuals with intellectual disabilities. In this study, having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality.*”

The intent was to describe the impact of the population of established patients across 154 health systems. The population includes all patients with a medical record that predates an encounter with a Covid-19 diagnosis. Jefferson’s Institutional Review Board certified that the study methodology did not constitute human subjects research and as such was not subject to review on January 25, 2021.

The “Patients with Intellectual Disabilities” group is defined as distinct patients seen by any member location between January 2019 and November 2020, with a diagnosis code of F70-F79 (intellectual disability). Codes are not always consistently recorded across all encounters, so patients who are not recorded as having an intellectual disability when they are diagnosed with

Table 1. Payer Groups Suggesting Low Socioeconomic Status and Comorbidities

Payer Groups Suggesting Low Socioeconomic Status
Medicaid Traditional/Indemnity
Medicaid Transplant Network
Medicaid/Managed Care
Medicaid (not otherwise specified)
Title V Maternal & Child Health Traditional/Indemnity
Title V Maternal & Child (HMO)
Title V Maternal & Child Health (not otherwise specified)
County Medically Indigent Services Traditional/Indemnity
County Medically Indigent Services (not otherwise specified)
Charity Traditional/Indemnity
Charity (not otherwise specified)
Self-Pay — Uninsured (not otherwise specified)

Comorbidities
Congestive heart failure
Pulmonary circulation disorders
Hypertension (with or without complications)
Neurological disorders
Lung disorders
Diabetes (with or without complications)
Thyroid disease
Chronic kidney disease
Liver disorders
Oncology (leukemia, lymphoma, and solid organ)
Coagulopathy
Obesity
Malnutrition
Fluid/electrolyte disorders
Deficiency anemia

Source: The authors.

Covid-19 might have had a diagnosis of intellectual disability in a previous encounter. In this analysis we have summarized each patient record so that any diagnosis of intellectual disability on any encounter since January of 2019 can identify a patient in this group.

The “Patients with No Intellectual Disabilities” group is all member system patients from the same time period, excluding those in the Patients with Intellectual Disabilities group.

Patients who have no record of care at the institution they presented to with Covid-19 prior to their Covid-19 diagnosis were defined as “New Patients.”

Patients in any of the payer categories listed in Table 1 were defined as “Payer Group Suggesting Low Socioeconomic Status.”

Elixhauser comorbidities definitions and their equivalent ICD-10 diagnosis groupings across the continuum of care were utilized. Comorbidities that were included are those that were documented prior to the diagnosis of Covid-19, and those that were included are listed in full in Table 1.⁸ Behavioral health comorbidities were excluded, as was any comorbidity that did not affect at least 10% of the patient population, diagnoses, or deaths.

Diagnosis and admission were defined by patient status within the CDB/RM. Note that “Covid-19 diagnosis” in this analysis specifically refers to presentation with Covid-19 at the provider institution, meaning that patients who were screened and treated at other institutions or those who had mild cases and did not present were excluded from analysis. Admitted patients are counted only once, regardless of readmissions. ICU stay and inpatient mortality were also defined by patient status. Patients with multiple ICU stays are counted only once.

Multivariate logistic regression models include intellectual disability as a factor in the model to evaluate the associations of intellectual disability with increased risk of Covid-19 diagnosis, admission, ICU stay, and mortality, in the context of all of the other comorbidities as well as demographic factors (age, gender, race/ethnicity, payer-based socioeconomic status). Odds ratio for mortality among admitted patients is calculated on patient records with a Covid-19 diagnosis and admission with Covid-19 (without regard for diagnosis rank).

Results

The study population include records of 64,858,460 patients in total, of which 128,074 were patients with intellectual disabilities and 64,730,386 were patients without intellectual disabilities.⁹ The data set included 443,965 “new patients” with Covid-19, but these were excluded from analysis as corresponding records for new patients without Covid-19 did not exist within the data. This left a data set of 64,414,495 patients, of which 127,003 were patients with intellectual disabilities and 64,287,492 were patients without intellectual disabilities.



The risks to patients with intellectual disabilities incorporate not only risks associated with intellectual disability itself, but also the risks associated with these comorbidities that were overrepresented among those with intellectual disabilities."

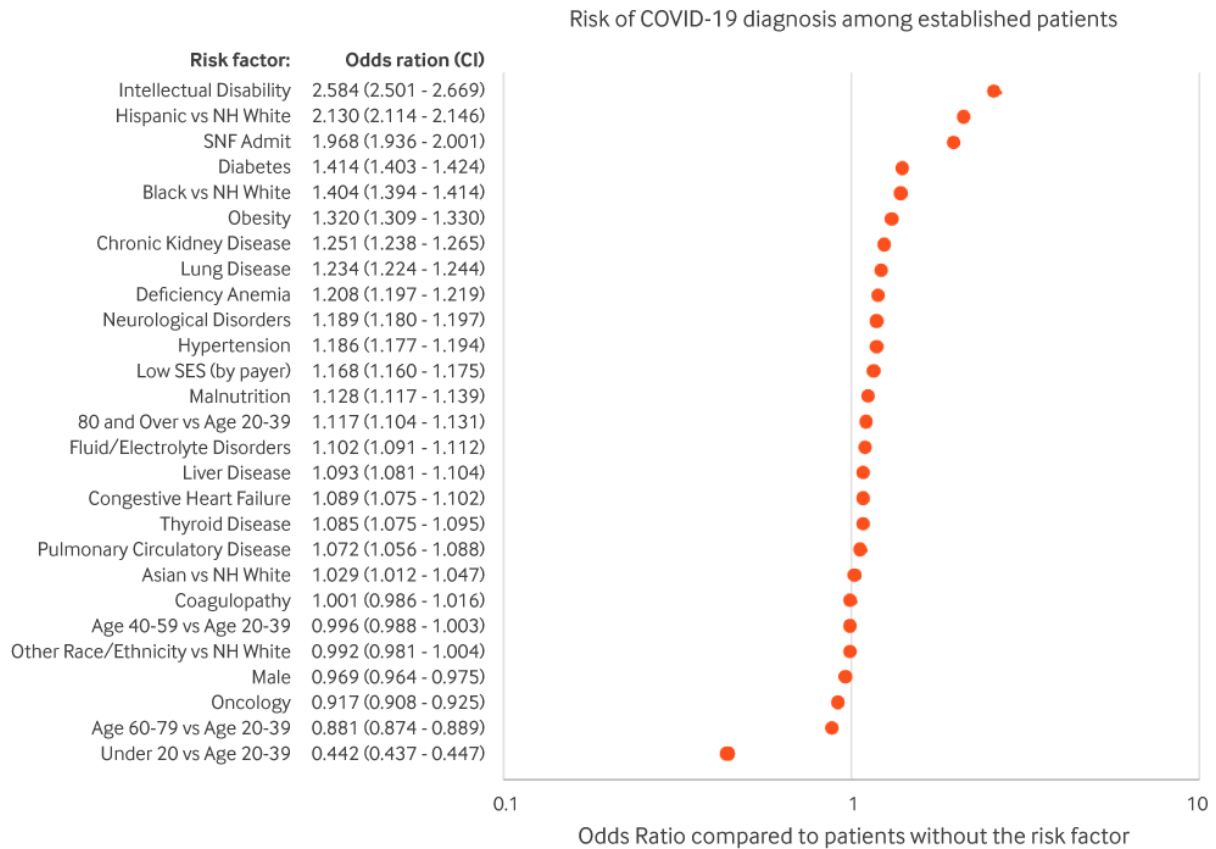
Of these, 558,672 (0.87%) presented with a diagnosis of Covid-19. Established patients with intellectual disabilities had higher rates of Covid-19 incidence than those without intellectual disabilities and with Covid-19 (3.1% vs 0.9%, $p < .001$), and were more likely to be admitted to the hospital if diagnosed (63.1% vs. 29.1%, $p < .001$). Those with intellectual disabilities and a diagnosis of Covid-19 had higher rates of ICU stay (14.5% vs. 6.3%, $p < .001$), and patients with intellectual disabilities were more likely to die following diagnosis of Covid-19 (8.2% vs. 3.8%, $p < .001$). Those with intellectual disabilities were more likely to be existing patients of the institution where they presented with Covid-19 (22% new patients compared with 44% of those without intellectual disabilities), less likely to be in a higher age group (1% over 80 and 18% from 60–80 compared with 5% and 25% in the general population, respectively), and more likely to have a health care payer status associated with low socioeconomic status (44% vs. 28%, $p < .001$). Patients with intellectual disabilities also had higher rates of all comorbidities other than cancer prior to Covid-19.

The adjusted odds ratio for intellectual disabilities and Covid-19 diagnosis among established patients was 2.584 (95% CI 2.501–2.669). The adjusted odds ratio for intellectual disabilities and

Covid-19 admission among those diagnosed was 2.739 (95% CI 2.490–3.014). There was no significant association of intellectual disabilities with ICU stay among admitted patients, with an odds ratio of 1.039 (95% CI 0.941–1.147). The adjusted odds ratio of inpatient mortality among those with intellectual disabilities admitted with Covid-19 was 1.324 (95% CI 1.165–1.505). Among all established patients, the odds ratio of mortality due to Covid-19 among those with intellectual disabilities was 5.909 (95% CI 5.277–6.617). These regressions are presented in Table 2 and Figure 1, Figure 2, Figure 3, and Figure 4.

FIGURE 1

Risk of Covid-19 Diagnosis Among Established Patients



Source: The authors

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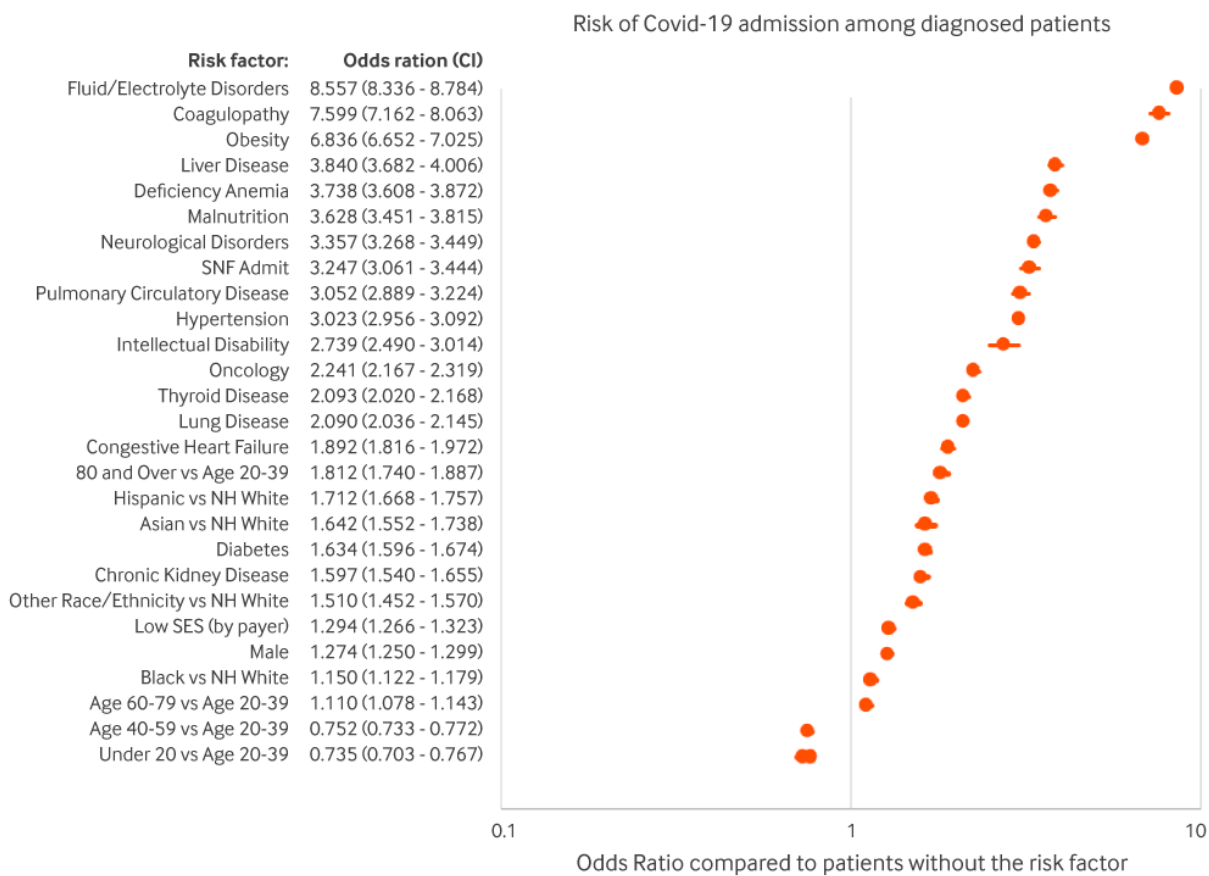
Table 2. Study Population Descriptives, Covid-19 Incidence, and Covid-19 Outcomes

	Patients with No Intellectual Disabilities	Patients with Intellectual Disabilities
Total Patients in Data Set	64,858,460	
Total Established Patients Prior to Covid-19	64,414,495	
Distinct Patients	64,730,386	128,074
• Established Patients Pre-Covid-19	64,287,492	127,003
• Established Patients with Covid-19	554,775 (0.9%)	3,897 (3.1%)
• Additional New Patients with Covid-19*	442,894	1,071
• Total Covid-19 Diagnoses	997,669	4,968
• “New” Covid-19 patients	44%	22%
Covid-19 Admissions — Established Patients Only	165,163 (29.1% of diagnoses)	2,459 (63.1% of diagnoses)
• ICU Stay	35,139 (6.3% of diagnoses)	565 (14.5% of diagnoses)
• Mortality	21,277 (3.8% of diagnoses)	321 (8.2% of diagnoses)
% Female (number) — Established Patients Only	56.7% (36,478,292)	43.4% (55,050)
Distribution of Ages — Established Patients Only		
• Under 20	11,931,901 (18%)	26,932 (21%)
• Age 20–39	16,693,973 (25%)	42,266 (33%)
• Age 40–59	17,630,106 (27%)	35,986 (28%)
• Age 60–79	16,572,219 (25%)	22,906 (18%)
• 80 and Over	3,606,912 (5%)	1,620 (1%)
Payer Group Suggesting Low Socioeconomic Status	18,252,574 (28%)	56,917 (44%)
Mortality Among Established Patients (Includes ED Mortalities)		
• Under 20	0.0002% (27)	0.0038% (1)
• Age 20–39	0.0025% (403)	0.0602% (25)
• Age 40–59	0.02% (2839)	0.30% (106)
• Age 60–79	0.07% (10760)	0.75% (167)
• 80 and Over	0.21% (7428)	1.40% (22)
Mortality Among Admitted Patients (Established Only)		
• Under 20	0.65% (22)	0.82% (1)
• Age 20–39	1.76% (387)	5.24% (24)
• Age 40–59	6.65% (2758)	12.10% (102)
• Age 60–79	16.06% (10528)	16.67% (158)
• 80 and Over	24.36% (7023)	25.00% (22)
Rates of Comorbidities Pre-Covid-19:		
• Congestive Heart Failure	2,108,408 / 3.3%	6,994 / 5.5%
• Pulmonary Circulatory Disorders	1,216,665 / 1.9%	4,093 / 3.2%
• Hypertension	14,425,308 / 22.4%	38,654 / 30.4%
• Neurological Disorders	9,405,049 / 14.6%	68,035 / 53.6%
• Lung Disease (Asthma & COPD)	5,613,511 / 8.7%	21,655 / 17.1%
• Diabetes	7,934,598 / 12.3%	26,162 / 20.6%
• Thyroid Disorders	4,479,283 / 7.0%	20,041 / 15.8%
• Chronic Kidney Disease	2,682,036 / 4.2%	8,919 / 7.0%
• Liver Disease	2,917,538 / 4.5%	10,137 / 8.0%
• Oncology	5,908,421 / 9.2%	7,904 / 6.2%
• Coagulopathy	1,341,944 / 2.1%	7,826 / 6.2%
• Obesity	5,324,014 / 8.3%	24,306 / 19.1%
• Malnutrition	3,240,367 / 5.0%	19,703 / 15.5%
• Fluid/ Electrolyte Disorders	4,339,274 / 6.7%	29,071 / 22.9%
• Deficiency Anemia	4,168,169 / 6.5%	21,154 / 16.7%

*Analysis excludes these patients. Source: The authors.

FIGURE 2

Risk of Admission Among Diagnosed Patients — Established Patients Only

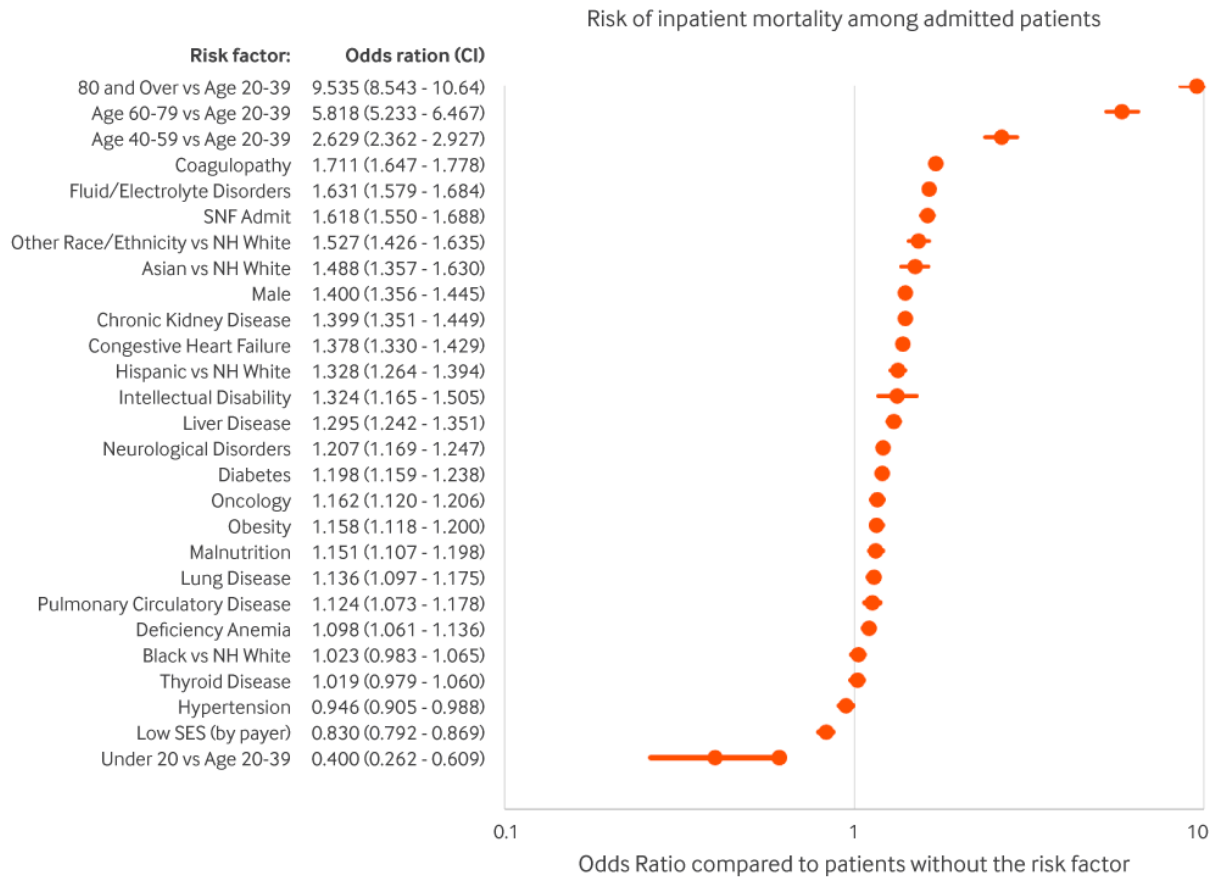


Source: The authors

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FIGURE 3

Risk of Mortality Among Admitted Patients — Established Patients Only

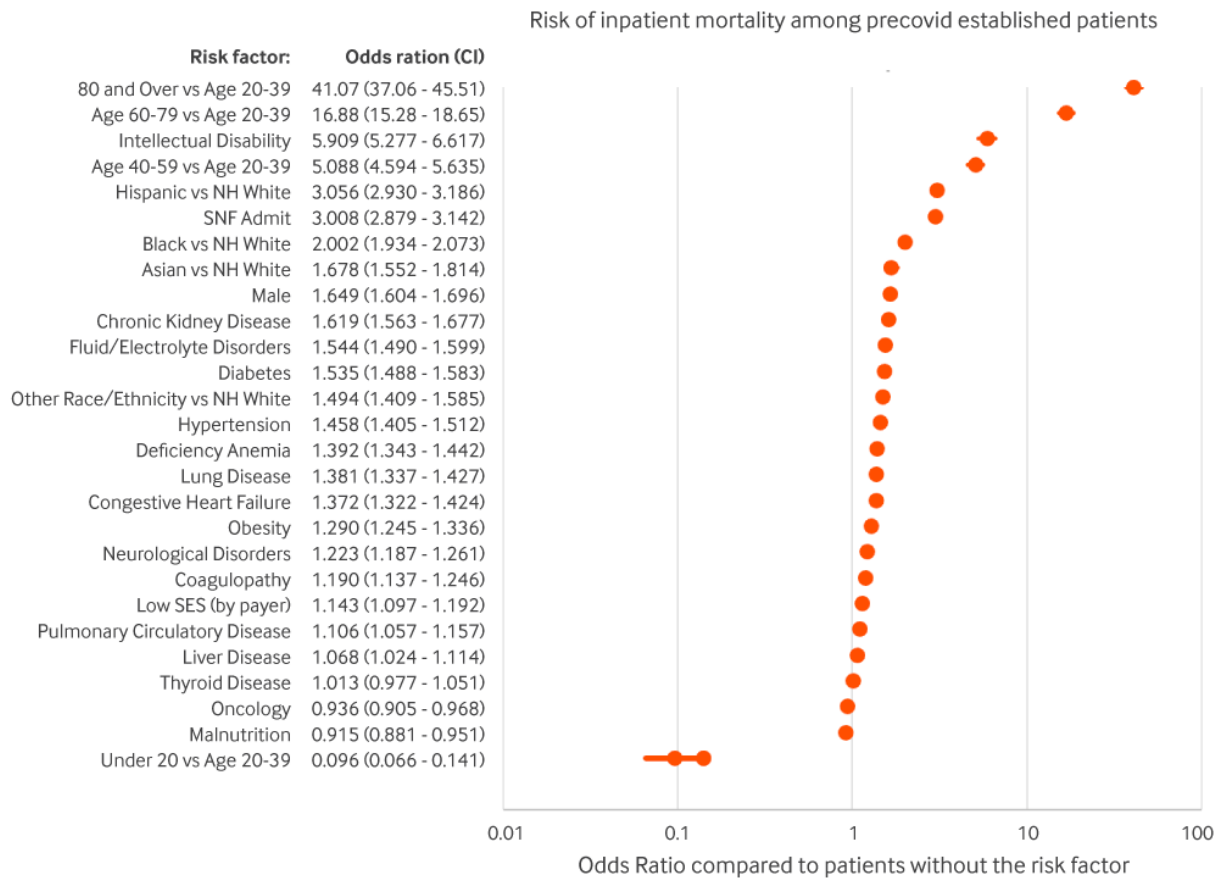


Source: The authors

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FIGURE 4

Risk of Covid-19 Mortality — All Established Patients



Source: The authors

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Discussion

Having an intellectual disability is the strongest independent risk factor for having a Covid-19 diagnosis among a large patient population in the United States. These data corroborate findings in the available literature that indicate that those with intellectual disabilities are more likely to contract Covid-19. Those with intellectual disabilities were the identified clinical group at highest risk of presenting with Covid-19 in this study compared to those without intellectual disabilities. These risks persisted after regression to control for common comorbidities, but it is worth noting that these comorbidities were especially common among those with intellectual disabilities.

The risks to patients with intellectual disabilities incorporate not only risks associated with intellectual disability itself, but also the risks associated with these comorbidities that were overrepresented among those with intellectual disabilities. If diagnosed with Covid-19, patients with intellectual disabilities were more likely to be admitted to the hospital, and while they were not

more likely to be admitted to the ICU following an admission, they were more likely to experience mortality due to Covid-19 following an admission. These odds of mortality in this population is significantly higher than other conditions such as congestive heart failure, kidney disease, and lung disease.

“ *Beyond the direct risk of Covid-19, the pandemic has had negative effects on the ability of individuals with intellectual disabilities to receive the health care and daily support that they typically receive.* ”

The risk of exposure in this population can be explained by a number of factors, including the need for daily care that many with intellectual disabilities have, which requires regular contact with home-care support personnel and others, use of shared transportation, and in many cases residence in high-contact housing such as long-term care facilities. Some individuals with intellectual disabilities have sensory issues that make tolerating mask-wearing for long periods of time difficult. Cognitive impairments and communication difficulties also raise the question of need for family or caregiver support when hospitalized.

Beyond the direct risk of Covid-19, the pandemic has had negative effects on the ability of individuals with intellectual disabilities to receive the health care and daily support that they typically receive. Providers who are not cognizant of this medical limitation may incorrectly turn them away, even though this limitation is covered by the Americans with Disabilities Act. A lack of typical supportive services may lead to increased behavioral issues and treatment with psychotropic medication with negative side effects, including weight gain. These risk factors and the additional barriers previously discussed indicate that increased resources are needed to vaccinate this vulnerable population and those who provide direct care, to prevent Covid-19 infection.

It is notable that the inpatient mortality is elevated in this group, but ICU admission was not elevated. This raises questions about whether critically ill patients with intellectual disabilities are less likely to be transferred to a higher level of care, or if this reflects differences in advanced care planning in this population. Further study is needed in this area.

The data considered here have a number of limitations. We are unable to track patients across different health care providers, meaning that the incidence rates of Covid-19 among established patients presented are not indicative of the overall incidence of Covid-19. For comparison, the rate of Covid-19 diagnosis reported in this study was 0.87% as of November 2020, while the overall incidence reported in the United States at that time was 2.91%.¹⁰ This study also excluded patients who presented at institutions in the data set with a diagnosis of Covid-19 who were not established patients of those institutions.

There is a general limitation on reporting of intellectual disabilities diagnosis; many patients with intellectual disabilities may not have that diagnosis reflected in their medical record. In our sample, 0.2% of patients had a recorded diagnosis of intellectual disabilities in their medical record; while

prevalence of intellectual disabilities among adult populations is not well established, studies have estimated it at 0.52%–1.37%.¹¹

Conclusion

Covid-19 has had a devastating impact on individuals with intellectual disabilities. In this study, having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality. Patients with intellectual disabilities and their caregivers should be prioritized for vaccination and health care services.

While the needs of this population due to Covid-19 clearly require immediate attention, these results also reflect existing limitations of the health care system as they pertain to individuals with intellectual disabilities.

Jonathan Gleason, MD

Chief Quality Officer, Jefferson Health, Philadelphia, Pennsylvania, USA

Wendy Ross, MD

Director, Center for Autism & Neurodiversity, Jefferson Health, Philadelphia, Pennsylvania, USA

Alexander Fossi, MPHc

Research Coordinator, Center for Autism & Neurodiversity, Jefferson Health, Philadelphia, Pennsylvania, USA

Heather Blonsky, MAS

Data Scientist, Vizient, Inc., Irving, Texas, USA

Jane Tobias, DNP, RN, MSN, CPNP-PC

Assistant Professor, Jefferson Health, Philadelphia, Pennsylvania, USA

Mary Stephens, MD

Assistant Professor, Family and Community Medicine, Jefferson Health, Philadelphia, Pennsylvania, USA

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