Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

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Brief Report

COVID-19 positivity rates, hospitalizations and mortality of adults with and without intellectual and developmental disabilities in Ontario, Canada

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ABSTRACT

Background: Across and within countries there is a need to understand how the COVID-19 pandemic has impacted populations of individuals with intellectual and developmental disabilities (IDD).
Objective: Rates of COVID-19 positivity for adults with IDD, including Down syndrome, relative to adults without IDD in Ontario, Canada were compared. Health profiles and case-based rates of hospitalizations, intensive care unit admissions, and mortality within 30 days of testing positively were compared for those with IDD, including Down syndrome, versus those without IDD.
Methods: This retrospective cohort study linked health administrative databases using unique encoded identifiers to describe population-level COVID-19 positivity, related hospital use and mortality from January 15, 2020 to January 10, 2021. Incidence rate ratios (RR) and 95% confidence intervals were calculated.
Results: Relative to adults without IDD, COVID-19 positivity rates were 1.28 times higher for adults with IDD and 1.42 times higher for adults with Down syndrome.
Compared to adults without IDD, adults with IDD were more than twice as likely to be hospitalized following COVID-19 (RR:2.21 (95%CI: 1.93,2.54)) and to die (RR:2.23 (95%CI: 1.86,2.67). These RRs were greater for adults under 65. For adults with Down syndrome, mortality rates were 6.59 (95%CI: 4.51,9.62) times higher than those without IDD.
Discussion: In Ontario, Canada, hospitalization and mortality rates associated with COVID-19 are higher for adults with IDD than other adults. These findings should inform vaccination strategies that often prioritize older adults in the general population resulting in people with IDD, who are often in younger age groups, being overlooked.

International data from the United Kingdom and the US in particular have shown that SARS-COV-2 (COVID-19) has disproportionately impacted people with intellectual and developmental disabilities (IDD) with higher rates of hospitalizations[1] and greater mortality risk compared to those without IDD.[1,2,3,4] While living in congregate care settings and having higher rates of comorbidities such as epilepsy, respiratory illnesses, cerebral palsy, diabetes, or psychiatric disorders are important factors,[5,6,7]evidence of higher rates of death from COVID-19 for people with IDD have remained even after adjusting for demographic and clinical contributors.[1,2] Risk of mortality has been reported to be especially high for those with Down syndrome.[6,8,9]

How people with IDD experience COVID-19 and related outcomes may differ across jurisdictions due to variations in regional health and social disability policies and in targeted public health efforts to minimize the spread in community and congregate care settings. To date, no research has examined if people with IDD are

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also disproportionately affected by COVID-19 in Canada.

Data on hospitalization and mortality rates due to COVID-19 across countries is sorely needed because the risk of adverse outcomes related to COVID-19 in a specific jurisdiction and in a given group often informs vaccination prioritization strategies. Given that it is widely known that older adults have elevated susceptibility to the virus and risk for adverse outcomes,[3] many countries have adopted primarily age-based vaccination prioritization strategies; they are not necessarily prioritizing people with IDD who are often in younger age groups, but still experience a number of negative COVID-19 related outcomes.

This paper will focus on Ontario, Canada's most populous province, with a 2020 population of 15 million.[10] Ontario has had lower population-based rates of COVID-19 than the United Kingdom or the US, likely due in part to jurisdictional differences in population density and the timing and types of responses to the pandemic. For example, in March 2020 Ontario implemented physical distancing, infection prevention and control (IPAC) requirements in public settings, closed the Canada-US border, closed non-essential work-places and schools to in-person learning and made insured, virtual health care available. In the IDD sector, the provincial government implemented IPAC protocols, closed any activities outside of the home, and prohibited staff from working in multiple settings quite rapidly. Restrictions following the first wave of the pandemic were gradually lifted in the summer of 2020 and were re-implemented to lesser degrees during the second wave in fall 2020 and a third wave beginning in winter 2021. Another key difference between Ontario and the US is that physician-provided and hospital-based health care are available at no cost to all residents eligible for the provincially administered health insurance plan.

Aim

This retrospective cohort study first describes the population COVID-19 testing and positivity rates for adults with IDD and for adults with Down syndrome relative to adults without IDD in Ontario, Canada. It then compares the sociodemographic and health profiles and case-based rates of clinical outcomes (all-cause hospitalizations, all-cause ICU admissions, and all-cause mortality within 30 days of testing positive for COVID-19) of adults with IDD relative to adults without IDD in Ontario, Canada, overall and by age group categories. A sub-analysis compares a subset of those with IDD who have Down syndrome to the same comparator, adults with no IDD. As we continue to enter new phases of the pandemic, our focus is to provide descriptive results for people with IDD as an initial investigation to help inform future policy.

Methods

Study design and setting

This is a retrospective cohort study of adults in Ontario, Canada with and without IDD as identified using health administrative databases. All Ontario residents are eligible for the provincial health insurance plan, which provides universal coverage for basic and emergency health services, including physician, emergency department and inpatient care, and information about the health services received by all Ontario residents is captured within these databases. The 1% of adults not eligible for these services are recent arrivals to Ontario, First Nations on reserves, Inuit, certain refugee claimant groups, inmates in federal penitentiaries, eligible veterans and serving members of the Canadian Forces. Provincial health and health service use databases were linked using unique encoded identifiers and analyzed at ICES. ICES is a not-for-profit, research institute funded by an annual grant from the Ontario Ministry of Health and the Ministry of Long-Term Care. As a prescribed entity under Ontario's privacy legislation, ICES is authorized to collect and use health care data for the purposes of health system analysis, evaluation and decision support. Secure access to these data is governed by policies and procedures that are approved by the Information and Privacy Commissioner of Ontario. The use of data in this project was authorized under section 45 of Ontario's Personal Health Information Protection Act, which does not require review by a Research Ethics Board.

Study cohort

Consistent with earlier research,[11] individuals were considered to have IDD if they had received a diagnosis of intellectual disability, fetal alcohol syndrome, autism spectrum disorder, and/or chromosomal and autosomal anomalies (e.g. Down syndrome, Fragile X syndrome) recorded in any of the health administrative databases from their inception to the most recent year of data available (see Appendix). Adults 18–105 years of age were considered to have IDD if one of these diagnoses was recorded in either $\geq$2 physician visits or $\geq$1 emergency department visit or hospitalization since birth or database inception until January 10, 2020.

Adults were considered to have Down syndrome if they had at least one hospital visit, one same day surgery, or one emergency department visit with a Down syndrome diagnosis code (ICD-9: 758.0, ICD-10: Q90.0–Q90.9). Diagnostic information from the outpatient database was not included because the outpatient billing code (758) used for Down Syndrome also captures a number of other chromosomal anomalies.[10] While this algorithm would not capture all cases of Down syndrome, identification with administrative health data can yield high specificity overall.[13]

COVID-19 (SARS-CoV-2) positivity

Individuals were considered positive for SARS-CoV-2 if they had a laboratory-confirmed viral RNA polymerase chain reaction SARS-CoV-2 test according to Ontario Laboratories Information System (OLIS) from January 15, 2020 to January 10, 2021. The earliest testing episode was used to signify SARS-CoV-2 status. The earliest specimen with a positive result was considered if multiple positive tests were found for one individual (for more details, see[14]).

Outcome measures

All-cause hospital admissions, hospital admissions requiring admissions to intensive care units (ICUs) and deaths were measured from January 15, 2020 to January 10, 2021. These were attributed to SARS-CoV-2 if they occurred within 30 days of a person having a positive SARS-CoV-2 test.

Other measures

As of January 10, 2021, age group (18–54, 55–64 and 65+), sex, rurality status and neighbourhood income quintile were measured. Morbidity was measured using The John Hopkins ACG® System Resource Utilization Bands (RUBs), with higher levels representing the highest levels of expected resource use.[15] In addition, the prevalence of specific chronic conditions was calculated using validated disease algorithms for Ontarians with asthma,[16] diabetes,[17] hypertension,[18] chronic obstructive pulmonary disease (COPD),[19] dementia[20] and epilepsy,[21] along with previously published algorithms for cerebral palsy[22] and mental health and/or addiction disorders developed in prior research with adults with IDD.[12]

Analysis

For Ontario adults, we assessed COVID-19 positivity rates in adults who have IDD, who have Down syndrome and who do not have IDD. Among the adults who tested positive for COVID-19, we compared the sociodemographic and clinical characteristics as of their testing episode date for those with and without IDD. We also calculated standardized differences for these characteristics, where <0.10 implied negligible differences between groups.[23,24] We provided rates of various clinical conditions as context given the knowledge that they are associated with adverse COVID-19 outcomes. Rates were calculated for all-cause hospitalizations, all-cause ICU admissions among those with hospitalizations, and all-cause mortality within 30 days of testing positive for COVID-19 from January 15, 2020 to January 10, 2021. Ratios and 95% confidence intervals were calculated comparing rates between those with vs. those without IDD overall and by age groups (18–54, 55–64, and 65+), and for those with Down syndrome versus those without IDD. Chi square tests were used to assess the statistical significance of group differences. P-values of 0.05 or less were considered to indicate statically significant group differences. Analyses were conducted using SAS version 9.4 (SAS Institute Inc., Cary, NC).

Results

As illustrated in Table 1, rates of adults who tested positive for COVID-19 were higher for adults with IDD (19.35 per 1000 adults with IDD) than for adults without IDD (15.07 per 1000 adults with no IDD, incidence ratio (1.28 (95%CI: 1.23, 1.34), $p < 0.0001$). Adults with Down syndrome had the highest rates (21.33 per 1000 adults with Down syndrome, incidence ratio (1.42 (95%CI: 1.17, 1.69), $p = 0003$)).

Among Ontario adults who tested positive for COVID-19, compared to adults with no IDD, the IDD group was more likely to be under 30 and less likely to be over 80. With regard to morbidity, people with IDD were less likely to be in the lowest morbidity category (1.6% vs. 4.5%), and more likely to be in the highest morbidity category (20.6% vs. 9.0%). Adults with IDD also had higher rates of several health conditions or disabilities that could exacerbate COVID-19 complications including asthma (21.5% vs 15.3%), diabetes (22.2% vs. 16.4%), COPD (13.0% vs. 6.9%), dementia (23.2% vs. 7.0%), cerebral palsy (11.4% vs. 0.1%), epilepsy (19.3 vs. 0.9%) and mental illness and/or addiction (60.3% vs. 30.9%) than other adults (all standardized differences>0.10, Table 2).

As indicated in Table 3, hospitalization rates were higher for those with IDD relative to those without IDD overall, as well as in the two younger age groups (overall: 2.21 times higher). Adults under age 55 and adults aged 55 to 64 were 4.60 times as likely and 2.50 times as likely, respectively, to be hospitalized than their counterparts without IDD in the same age group.

Amongst those who were hospitalized after a positive COVID-19 test, there were no differences in ICU rates across the IDD and no IDD groups overall, or by age group.

Adults with IDD were 2.23 times more likely to die than those without IDD. For adults under 55, those with IDD were 16.77 times more likely to die than their counterparts without IDD. This discrepancy was still large, albeit slightly smaller for adults aged 55–64, as those with IDD were 9.24 times more likely to die than their counterparts without IDD.

As illustrated in Table 4, adults with Down syndrome were 3.65 times more likely to be hospitalized as adults without IDD. The difference in ICU rates (35% vs. 23.8%) for those hospitalized, however, was not significant. Adults with Down syndrome were 6.59 times more likely to die than those without IDD (18.2% vs. 2.8%).

Discussion

Data from Ontario mirror patterns reported in US and UK suggesting that hospitalization and mortality rates for COVID-19 are higher for adults with IDD than in the general population,[1,5] especially when looking at younger and middle-aged adults. These differences are even more apparent for individuals with Down syndrome who in Ontario died at a rate 6.6 times higher than those without IDD. This study included administrative health data for all Ontario adults up to January 2021 in a public health care system. This study, the first within Canada, illustrates the importance of collecting and reporting outcomes data for people with IDD as part of public health monitoring.

Given the heightened risks experienced by adults with IDD once diagnosed with COVID-19, particularly for younger and middle aged adults, vaccination distribution programs must prioritize eligibility and accessibility of both doses of the vaccine to this group and not simply rely on age-based criteria. Furthermore, efforts are needed to facilitate vaccinations that go beyond eligibility requirements, so that it is easier for this high risk group to access vaccines in a way that is not stressful to them.[25] These findings are also important with regard to who is prioritized for potential vaccine booster programs in the future.[26] Given that in Ontario, as of July 4, 2021, the majority of adults with IDD were not fully vaccinated,[27] this information could influence the distribution of the first and second vaccine dose.

In the present study, adults in the IDD cohort who tested positive for COVID-19 had higher rates of every health condition studied, besides hypertension, than other adults who tested positive for COVID-19, similar to what was reported in a recent US study.[1] US and UK studies focused specifically on those with IDD who have died as a result of COVID-19 have also found high rates of comorbid conditions in those who died.[5,6,7] Such comorbidities can influence their susceptibility to and response to the virus so it will be important for future work on IDD to evaluate the elevated risk

Table 1
SARS-COV-2 testing and positivity rates for adults 18+ with intellectual and developmental disabilities and with Down syndrome compared to adults without intellectual and developmental disabilities in Ontario, Canada as of January 10, 2021.

	Adults without Intellectual and Developmental Disabilities N = 12,428,078		Adults with Intellectual and Developmental Disabilities N = 96,013			Adults with Down syndrome N = 5671		
	N	%	N	%		N	%	
Tested for SARS-COV-2	3,111,198	25.0334	28,342	29.519		1537	27.103	
	N	Cases/1000	N	Cases/1000	Incidence ratio (95% CI)	N	Cases/1000	Incidence ratio (95% CI)
Tested positively for SARS-COV-2	187,290	15.07	1858	19.35	1.28 (1.23, 1.34)	121	21.33	1.42 (1.17, 1.69)

Table 2
Sociodemographic and clinical characteristics for adults 18+ who tested positive for COVID-19 with and without intellectual and developmental disabilities in Ontario, Canada.

		Adults with Intellectual and Developmental Disabilities confirmed positive for COVID-19 N = 1858		Adults without Intellectual and Developmental Disabilities confirmed positive for COVID-19 N = 187,290		Standardized Difference[a]
		N	%	N	%	
SOCIODEMOGRAPHIC CHARACTERISTICS						
Age continuous	Mean SD	47.5	20.25	47.2	19.86	0.015
	Median Q1-Q3	49	28–64	45	30–60	0.024
Age group	18–29	534	28.7%	43,961	23.5%	0.120
	30–39	220	11.8%	33,059	17.7%	0.164
	40–49	190	10.2%	30,487	16.3%	0.179
	50–59	291	15.7%	32,033	17.1%	0.039
	60–69	337	18.1%	20,456	10.9%	0.206
	70–79	182	9.8%	11,179	6.0%	0.142
	80–89	79	4.3%	9892	5.3%	0.048
	90+	25	1.3%	6223	3.3%	0.131
Sex	Male	1081	58.2%	89,341	47.7%	0.211
Rurality of residence	Missing information	13	0.7%	623	0.3%	0.051
	Rural	77	4.1%	7052	3.8%	0.019
	Urban	1768	95.2%	179,615	95.9%	0.036
Neighbourhood income Quintile	Missing information	13	0.7%	671	0.4%	0.047
	Lowest (1)	467	25.1%	45,667	24.4%	0.017
	2	425	22.9%	41,112	22.0%	0.022
	3	358	19.3%	39,944	21.3%	0.051
	4	314	16.9%	32,767	17.5%	0.016
	Highest (5)	281	15.1%	27,129	14.5%	0.018
CLINICAL CHARACTERISTICS						
Resource utilization bands	0 (missing)	45	(2.4%)	11,525	(6.2%)	**0.185**
	1 (Lowest)	30	(1.6%)	8384	(4.5%)	**0.167**
	2	164	(8.8%)	28,484	(15.2%)	**0.197**
	3	883	(47.5%)	91,779	(49.0%)	0.03
	4	354	(19.1%)	30,244	(16.1%)	0.076
	5 (Highest)	382	(20.6%)	16,874	(9.0%)	**0.33**
Asthma		400	21.5%	28,691	15.3%	**0.161**
Diabetes		413	22.2%	30,661	16.4%	**0.149**
Chronic obstructive pulmonary disease		242	13.0%	12,887	6.9%	**0.206**
Hypertension		519	27.9%	52,338	27.9%	0
Dementia		431	23.2%	13,123	7.0%	**0.464**
Epilepsy		359	19.3%	1613	0.9%	**0.644**
Cerebral Palsy		212	11.4%	249	0.1%	**0.498**
Down Syndrome		121	6.5%	0	0.0%	N/A
Mental Illness and/or Addiction		1120	60.3%	57,839	30.9%	**0.618**

[a] Bolded font indicates standardized differences > .10.

Table 3
Case rates of hospitalizations, admissions to the intensive care unit (ICU) and mortality within 30 days post COVID-19 positive test among adults 18+ who tested positive for COVID-19 with and without intellectual and developmental disabilities (Jan 15, 2020 to Jan 10, 2021), in Ontario, by age group, with incidence rate ratios and 95% confidence intervals.

	Adults with Intellectual and Developmental Disabilities N = 1858		Adults without Intellectual and Developmental Disabilities N = 187,290		Incidence rate ratio (95% CI)	P value
	Frequency	Rate per 1000 cases (95% CI)	Frequency	Rate per 1000 cases (95% CI)		
Hospitalization						
All adults	186	100.1 (86.2, 115.6)	8473	45.2 (44.3, 46.2)	2.21 (1.93, 2.54)	<0.0001
18–54 years	78	73.0 (57.7, 91.1)	1965	15.9 (15.2, 16.6)	4.60 (3.70, 5.72)	<0.0001
55–64 years	48	134.5 (99.1, 178.3)	1521	53.8 (51.1, 56.6)	2.50 (1.91, 3.27)	<0.0001
65+ years	60	138.6 (105.7, 178.4)	4987	141.2 (137.3, 145.2)	0.98 (0.77, 1.24)	0.8749
In those hospitalized, proportion in ICU						
All adults	37	198.9 (140.1, 274.2)	2027	239.2 (228.9, 249.9)	0.83 (0.62, 1.11)	0.2019
18–54 years	19	243.6 (146.7, 380.4)	468	238.2 (217.1, 260.8)	1.02 (0.69, 1.52)	0.9122
55–64 years	10	208.3 (99.9, 383.1)	512	336.6 (308.1, 367.1)	0.62 (0.35, 1.08)	0.0633
65+ years	8	133.3 (57.6, 26.27)	1047	209.9 (197.4, 223.1)	0.64 (0.33, 1.21)	0.1469
Mortality						
All adults	114	61.4 (50.6, 73.7)	5170	27.6 (26.9, 28.4)	2.23 (1.86, 2.67)	<0.0001
18–54 years	11	10.3 (5.1, 18.4)	76	0.61 (0.48, 0.77)	16.77 (8.93, 31.46)	<0.0001
55–64 years	28	78.4 (52.1, 113.4)	240	8.5 (7.4, 9.6)	9.24 (6.33, 13.47)	<0.0001
65+ years	75	173.2 (136.2, 217.1)	4854	137.5 (133.6, 141.4)	1.26 (1.02, 1.55)	0.0320

attributable to the disability relative to the independent contribution of pre-existing health conditions as well as other important factors such as living circumstance and sociodemographic indicators.

Similar to an earlier study in the UK based on a large primary care registry,[7] hospitalization and mortality rates for the subgroup of adults with Down syndrome were particularly concerning. How much of this is related to the age of the individuals identified as having Down syndrome, their residential setting or their comorbid health conditions in the current study is not known. Building on international research on Down syndrome and COVID-19 outcomes,[8] it will be important to further understand predictors of clinical outcomes within this group and also to follow these individuals forward to better understand the long-term impacts of COVID-19 infection on their health. There may be other subgroups within the IDD cohort who are also at very high risk who have yet to be studied.

Although hospitalizations and mortality were more common for adults with IDD across age groups, a pattern with regard to ICU use was less evident. The likelihood of ICU admission for those who were hospitalized did not differ between those with and without IDD, similar to what was reported in a US based study in an adjusted analysis.[1] One might anticipate higher ICU rates in those with IDD given their high rates of comorbidities and mortality risk. Discussions about advanced care planning have always been important but are particularly important during the pandemic.[28] Tailored tools can be helpful in this regard as people with IDD and families have recognized the importance of having these conversations before they are in a crisis situation.[29] It is equally important to consider the training of health care providers as it relates to this population so that if they encounter a patient with IDD who may benefit from an ICU admission, they would not deem them inappropriate for critical care simply because of their disability.

Limitations

This retrospective cohort study has several limitations. Specifically, administrative health data alone, without linkages to prior school records or social service documentation cannot identify everyone with IDD.[11] This means that some individuals with IDD may have been misclassified as not having IDD. If in fact, those with IDD are at greater risk of poor outcomes, this would reduce the observed differences between those with and without IDD. For those with Down syndrome, their diagnoses were determined based on diagnoses made in hospitals and emergency departments and not outpatient care. It is possible that additional individuals with Down syndrome who have never visited hospitals would be included within the broader IDD group, or in the group of those without IDD, again potentially minimizing between group differences. This study utilized OLIS data which is estimated to capture approximately 90% of positive cases in Ontario. However, it is not known if this would differentially capture cases of COVID-19 among people with IDD versus among others. Similarly, all-cause hospitalizations and mortality that occurred within a month of testing positive for COVID-19 were attributed to COVID-19, but could have been due to other causes. In addition, consequences of COVID-19 that occurred more than 30 days after a positive test would not have been captured in our analysis. This analysis is also likely underreporting outcomes, especially mortality, due to the lag in data reporting.

Table 4
Case rates of hospitalizations, admissions to the intensive care unit (ICU) and mortality within 30 days post COVID-19 positive test among adults (18+) who tested positive for COVID-19 with Down syndrome and without intellectual and developmental disabilities (Jan 15, 2020 to Jan 10, 2021), in Ontario, with incidence rate ratios and 95% confidence intervals.

	Adults with Down Syndrome N = 121		Adults without Intellectual and Developmental Disabilities N = 187,290		Incidence rate ratio (95% CI)	P value
	Frequency	Rate per 1000 cases (95% CI)	Frequency	Rate per 1000 cases (95% CI)		
Hospitalization	20	165.3 (101, 255.3)	8473	45.2 (44.3, 46.2)	3.65 (2.45, 5.46)	<0.0001
In those hospitalized, proportion in ICU	7	350 (140.7, 721.1)	2027	239.2 (228.9, 249.9)	1.46 (0.80, 2.66)	0.2463
Mortality	22	181.8 (113.9, 275.3)	5170	27.6 (26.9, 28.4)	6.59 (4.51, 9.62)	<0.0001

While this paper offers overall rates of hospitalizations and mortality, it does not adjust or otherwise account for key contributors such as residence, greater comorbidity and greater poverty. Future research should better understand predictors of risk within the IDD population, at different stages of the pandemic and across jurisdictions. Making comparisons across countries utilizing different definitions of IDD and different ways of capturing COVID-19 related hospitalizations and mortality is complicated. What does appear to be consistent across jurisdictions, regardless of how data are captured, is that the relative risks of hospitalization or death related to COVID-19 are clearly higher in those with IDD. How much it is impacted depends on how these constructs are measured, and importantly, how health and social care are provided in any jurisdiction.

Conclusion

This Ontario based study linked several population-level databases with information on COVID-19 testing, health care use and disability status and found that adults with IDD have fared worse than other individuals who test positive for COVID-19. It illustrates the importance of measuring and monitoring outcomes for this marginalized group in different countries and of using data to inform policy related to key decisions, such as vaccine prioritization for people with IDD. In addition to prioritizing this group for vaccines, efforts must be made to tackle health disparities and make sure that anyone with IDD who contracts COVID-19 receives the heath care they need. Until the pandemic is over, all adults with IDD would benefit from being prepared in case they require a hospital admission,[30] and continued focus on the prevention of COVID-19 should remain a priority.

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Disclaimer

The analyses, conclusions, opinions and statements expressed herein are solely those of the authors and do not reflect those of the funding or data sources; no endorsement is intended or should be inferred.

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Supplementary material

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