


Traumatic Brain Injury Incidence in Adults with Intellectual and Developmental Disabilities

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ABSTRACT: *Background:* In Ontario, there are approximately 66,000 adults living with a diagnosis of intellectual and developmental disabilities (IDD). These individuals are nearly twice as likely to experience an injury compared to the general population. Falls are an important contributor to injuries in persons with IDD and in the general population, and are consistently found to be the leading cause of traumatic brain injury (TBI). There is currently no literature that quantitatively examines TBI among persons with IDD. The purpose of this study was to compare the risk of TBI for adults with and without IDD in Ontario over time and by demographic information. *Methods:* Using administrative health databases, two main cohorts were identified: (1) adults with IDD, and (2) a random 10% sample of adults without IDD. Within each cohort, annual crude and adjusted incidence of TBI were calculated among unique individuals for each fiscal year from April 1, 2002 to March 31, 2017. *Results:* Over the 15-year study period, the average annual adjusted incidence of TBI was approximately 2.8 new cases per 1000 among Ontario adults with IDD, compared to approximately 1.53 per 1000 among those without IDD. In both cohorts, a higher proportion of TBI cases were younger (19–29 years) and male. *Conclusions:* During the study period, persons with IDD experienced a significantly higher risk of TBI compared to the general population indicating the possibility, and need, for targeted TBI prevention.

RÉSUMÉ : *Incidence des traumatismes cranio-cérébraux chez des adultes atteints de déficiences intellectuelles et développementales. Contexte :* En Ontario, on compte environ 66 000 adultes ayant reçu un diagnostic de déficience intellectuelle et développementale (DID). Ces personnes sont près de deux fois plus susceptibles de se blesser si on les compare à la population générale. À cet égard, les chutes demeurent un facteur important de blessure chez ces personnes et au sein de la population générale et continuent à être considérées comme la cause principale des traumatismes cranio-cérébraux (TCC). Il n'existe à l'heure actuelle aucune littérature scientifique ayant analysé d'un point de vue quantitatif les cas de TCC parmi les personnes atteintes de DID. L'objectif de cette étude est donc de comparer, au fil du temps et en fonction de caractéristiques démographiques, le risque de souffrir d'un TCC chez des adultes ontariens atteints et non-atteints de DID. *Méthodes :* À l'aide de bases de données administratives sur la santé, nous avons identifié deux cohortes principales : 1) des adultes atteints de DID et 2) un échantillon aléatoire de 10 % d'adultes n'étant pas atteints de DID. Au sein de chaque cohorte, nous avons calculé, pour chaque exercice annuel, l'incidence annuelle brute et ajustée des TCC chez des individus uniques. C'est ainsi que nous avons couvert la période allant du 1^{er} avril 2002 au 31 mars 2017. *Résultats :* Au cours de cette quinzaine d'années à l'étude, l'incidence annuelle ajustée moyenne de TCC a été approximativement de 2,8 nouveaux cas par 1000 adultes ontariens atteints de DID comparativement à environ 1,53 nouveaux cas par 1000 adultes n'étant pas atteints de DID. Dans les deux cohortes, une proportion plus élevée de TCC a été trouvée chez des jeunes adultes (19 à 29 ans) et chez des hommes. *Conclusions :* Au cours de cette période à l'étude, les individus atteints de DID ont connu un risque sensiblement plus élevé d'être victimes d'un TCC si on les compare à des individus de la population générale, ce qui indique la possibilité, de même que le besoin, d'une prévention des TCC davantage ciblée.

Keywords: Traumatic brain injury, Intellectual disabilities, Developmental disabilities, Incidence, Epidemiology

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INTRODUCTION

As a leading cause of death and disability, traumatic brain injury (TBI) is an important public health concern in developed countries such as Canada. In 2010/11, more than 200,000 people were living with TBI in Ontario, Canada alone, among whom more than 21,000 were incident cases, resulting in an incidence rate of 1.7 new cases per 1000 population.¹ The incidence of TBI has also been increasing steadily for several years. For instance,

the incidence of TBI reported for 2010/11 represented an increase of approximately 40% compared to 2004/05.^{1,2} Notably, concussions, which are a form of mild TBI, account for the majority of all TBI cases, and more recent data (2016) have shown that for concussions alone, incidence can be as high as 1177 cases per 100,000 Ontarians.³ Approximately two-thirds of reported TBI cases have been found to be male.^{1,4,5} Additionally, more than three-quarters of TBI cases occur among persons aged 18 and

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older,¹ which could present further difficulty as Canada's population continues to age.

Altered brain structure and/or function caused by TBI can result in debilitating impairments in cognition and physical and psychosocial functioning.⁶ Based on data from 2009, TBI-related emergency department visits in Ontario (Canada's most populous province) alone were conservatively estimated to have costed nearly \$300 million in direct costs and more than \$650 million in lost productivity.⁴ Based solely on emergency department visits, this represents only a fraction of the total TBI burden in Ontario. Additionally, if effective and targeted prevention methods are not implemented, TBI in Canada is expected to cost \$8.2 billion due to working age disability alone by 2031.⁷ Identifying individuals and groups who may have a higher risk for TBI is necessary to inform successful prevention.

Adults with intellectual and developmental disabilities (IDD), defined in this research as impairment in intellectual and adaptive functioning which developed prior to the age of 18,⁸ experience a number of health disparities compared to those without IDD. Among these are a greater risk for experiencing a number of health concerns including injuries and falls^{9,10} due to factors such as epilepsy,⁹⁻¹¹ poor balance and coordination,^{10,11} limitations in hazard recognition, and a greater propensity for self-injurious behavior.¹¹ Unfortunately, there is currently an overall lack of any regional or international data related to TBI at the population level for persons with IDD. The only article examining IDD and TBI concurrently was qualitative in nature, and focused on difficulties with access to health services.¹² No research could be found quantifying the burden or risk of TBI among persons with IDD.

Despite the lack of quantitative data regarding TBI among persons with IDD, some insight on the risk for TBI in this population may be derived from understanding the risk of injuries broadly, as well as falls. Based on past research, persons with IDD are up to 78% more likely than those without IDD to experience an injury,^{9,11} and have up to 70% increased incidence of falls versus the general population, with approximately one-quarter of these falls resulting in reported head injury.^{9,10} Notably, there is evidence that TBI results in greater direct and indirect costs among persons with IDD compared to the general population due to poorer services access and/or coordination.¹² Since falls are the leading cause of TBI in the general population,^{4,13} existing injury- and fall-related research strongly supports the hypothesis that TBI risk may be higher for persons with IDD.

The objective of this research is to address the lack of quantitative research on the intersection of TBI and IDD by comparing the incidence of TBI among Ontario adults with and without IDD over time and by demographic characteristics. Research examining potential risk factors for TBI, such as IDD, holds the potential to inform policy planning and resource allocation, as well as reduce TBI-related costs, by identifying potential target populations for prevention efforts.

METHODS

Study Design

A retrospective population-based cohort design was used to report annual incidence of TBI for each fiscal year from 2002/03 to 2016/17 for Ontario adults with and without IDD. This study was supported by ICES, which is funded by an annual grant from

the Ontario Ministry of Health and Long-Term Care (MOHLTC). ICES is renowned for maintaining high quality population-based administrative data for Ontario residents eligible for the Ontario Health Insurance Plan (OHIP). Data within these databases are de-identified and assigned a unique code which is used to link the data between other data sources.

Data Sources

A total of seven data sources were accessed including five health databases and two other data sources. These datasets were linked using unique encoded identifiers and analyzed at ICES. The five health databases used were the Canadian Institute of Health Information Discharge Abstract Database (CIHI-DAD), Same Day Surgery (SDS), the National Ambulatory Care Reporting System (NACRS), the Ontario Mental Health Reporting System (OMHRS), and OHIP database. These administrative health databases include various utilization and diagnostic data about Ontario residents including inpatient hospital discharges, day surgeries, emergency and ambulatory care visits, mental health hospitalizations, and physician billings.

The two other data sources used included the Registered Persons Database (RPDB), which contains demographic information (age, sex, postal code) on all Ontarians eligible for OHIP, and Canadian inter-censal population estimates (POPCAN) made available from Statistics Canada.

Study Populations

IDD was defined based on the definition used by the Government of Ontario to determine support services needs and eligibility.⁸ IDD in this research is thus defined as a lifelong impairment in intellectual functioning and adaptive behavior which developed prior to the age of 18, and is pervasive in many major life areas.

Three cohorts of Ontario adults aged 19 years and older were created using the above-mentioned health administrative databases. The three cohorts were: (1) All-IDD, consisting of all persons with a diagnosis of IDD; (2) TBI-Prior to IDD, a comparison cohort of persons with IDD and a history of TBI preceding their IDD diagnosis based on the first identified health care encounter with an IDD or TBI code; and (3) No-IDD, the primary comparison cohort consisting of a 10% random sample of the remaining Ontario adult population without IDD, identified using the RANUNI function in SAS® (a function for generating a random variate based on a uniform distribution¹⁴). This study intended to fully analyze cohort 2, TBI-Prior to IDD, in order to examine whether having a TBI prior to receiving a diagnosis of IDD impacts TBI incidence in adults with IDD; however, the ability to do so was limited by the small sample size for this population. To minimize re-identification risk, pursuant to ICES privacy regulations, data for cohort 2 are reported only for the last three study years.

To be included in the study, individuals had to be eligible for OHIP during a given study year as determined by the RPDB. Details on the methodology for identifying persons with IDD can be found in Lin et al.¹⁵

To create the TBI-Prior to IDD cohort, health records of persons identified with IDD were examined for history of TBI by looking back as far as the inception of the CIHI-DAD (inception 1988), SDS (inception 1991), and NACRS (inception

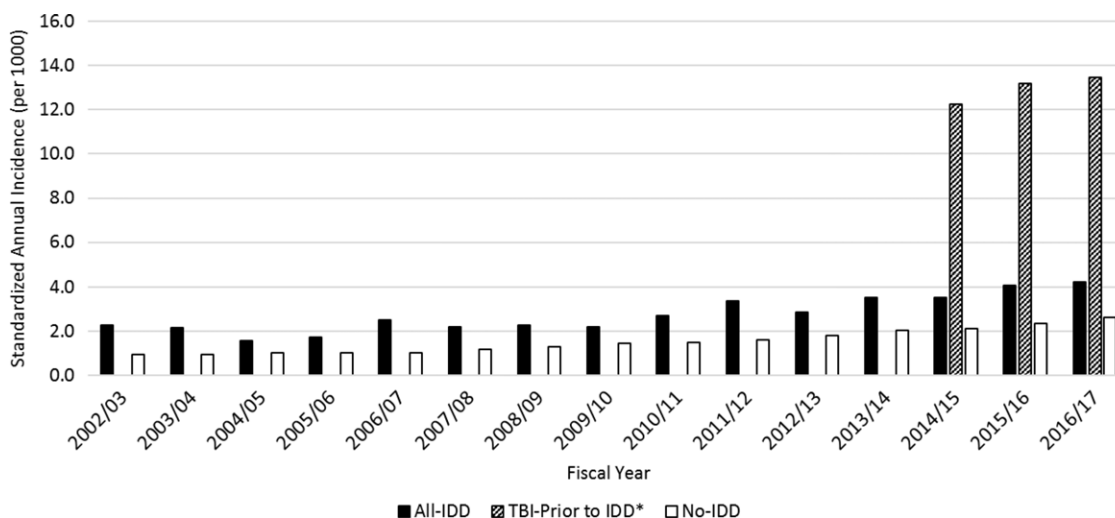


Figure 1: Age-/sex-standardized annual incidence (per 1000) of traumatic brain injury (TBI) among Ontario adults with intellectual and developmental disabilities (All-IDD), with a history of TBI prior to being diagnosed with IDD (TBI-Prior to IDD), and without IDD (No-IDD) (2002/03 to 2016/17).

*: Crude (unadjusted) incidence; small population size.

2002) databases to determine if there was any indication that a TBI event occurred prior to the diagnosis of IDD based on International Classification of Diseases (ICD)-9 and -10 codes. TBI was defined as ICD-10 codes S02, S04, S06, S07, T02, T06, or the ICD-9 equivalents. These codes have been used in previous research for identifying TBI in the above-mentioned databases and have been found to be highly specific, but only moderately sensitive.^{16,17} In order to maximize sensitivity, individuals were considered to have a history of TBI if at least one TBI-related code appeared in any health care visit.

Other Variables and Measures

Baseline demographic characteristics including age, sex, income quintile, and rurality were described for all groups based on data obtained using the RPDB and Canadian Census data. Income quintiles were based on neighborhood income level derived from summary data from the Canadian Census of household size-adjusted measures of household income.¹⁸ Data on income quintiles were included to provide an indication of an individual's socioeconomic situation. Rurality was determined using community size, which is based on census data.¹⁸ Communities with a population of <10,000 were designated as rural areas. Additionally, among TBI cases, mechanism of injury was examined in 2002/03 and 2016/17 using ICD-10 codes in the hospitalization episode record to identify the frequency with which falls resulted in TBI.

Data Analysis

Persons diagnosed with an incident TBI in all cohorts were identified using the same ICD-10 diagnostic codes listed above for TBI in CIHI-DAD (admitting), SDS (admitting), and NACRS (all diagnosis types). Incident cases were defined as the first new TBI diagnosis in a unique individual in a given fiscal year. Annual incidence of TBI was calculated in the three cohorts using the total number of yearly cases in a given cohort divided by the total yearly cohort population for fiscal years 2002/03–2016/17.

Annual incidence risk ratios were then calculated to provide a comparison of incident TBI across the three cohorts. Annual incidence of TBI in the No-IDD cohort was used as the reference group (denominator) for risk ratio calculations.

Annual cumulative age- and sex-specific incidence was also calculated for fiscal years 2002/03 and 2016/17 to compare the distribution of new cases of TBI per 1000 persons in specified age categories and between males and females in the All-IDD and No-IDD cohorts. Finally, annual age-/sex-standardized incidence rates (AS-SIR) and age- and sex-standardized risk ratios were calculated for all fiscal years. AS-SIR was standardized to the age and sex structure of the 2011 Canadian population to adjust for differences in age and sex distribution among study groups, increasing inter-cohort comparability.

The 95% confidence intervals (CIs) were calculated for all crude and standardized annual incidence and risk ratios.

RESULTS

At the beginning of the study period in 2002/03, the total study population consisted of 969,941 eligible Ontario adults, of whom 28,743 met the definition of IDD. Within the IDD cohort, 15,556 (54%) were male, 20,305 (71%) were under 50 years of age, 14,037 (49%) resided in the lowest two income quintiles, and 23,208 (81%) resided in urban regions. In comparison, of the 941,198 persons in the No-IDD cohort, 458,948 (49%) were male, 583,600 (62%) were under 50 years of age, 377,123 (40%) resided in the lowest two income quintiles, and 822,414 (87%) resided in urban regions. In 2016/17, baseline characteristics of both cohorts remained similar to those described for 2002/03. During the first study year, annual incidence of TBI among persons with All-IDD was approximately 2.2 cases per 1000 population, compared to 0.9 cases per 1000 among those with No-IDD. Over the 15-year study period, annual incidence of TBI rose steadily in all cohorts (Figure 1). Of the 1,208,958 people included in the study in 2016/17, 66,027 had IDD and annual incidence of TBI rose to approximately 4.3 cases per

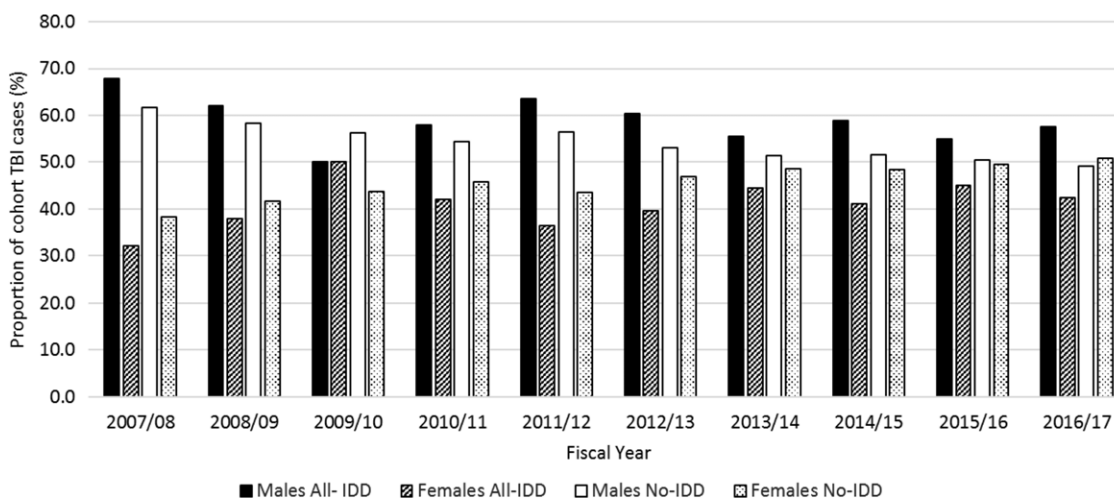


Figure 2: Sex distribution of traumatic brain injury (TBI) cases among Ontario adults with intellectual and developmental disabilities (All-IDD) versus without intellectual disabilities (No-IDD) (2007/08 to 2016/17).

1000 persons with All-IDD, and 2.6 cases per 1000 people with No-IDD.

As is shown in Figure 2, on an average, a higher proportion of individuals with TBI in both cohorts were male (2007/08 - IDD: 68%, No-IDD: 62%; 2016/17 - IDD: 57%, No-IDD: 50%). In the No-IDD cohort, the sex difference began to diminish beginning as early as 2009/10 and was not present in 2015/16 or 2016/17 (Figure 2). In the All-IDD cohort, the sex difference remained throughout all study years, with the exception of 2009/10.

Age distribution of TBI cases (not shown) was also examined for all study years. In both cohorts, there was a higher proportion of TBI cases aged 19–29 years (2002/03 - IDD: 28%, No-IDD: 27%; 2016/17 - IDD: 46%, No-IDD: 27%). Among persons with IDD, the proportion of TBI cases was greater for those aged 19–29 years in most fiscal years and lower for those aged 70+ in all fiscal years compared to persons with No-IDD.

Table 1 compares the annual crude and standardized incidence of TBI between the three study cohorts and provides the associated risk ratios. Over the 15-year study period, the adjusted annual incidence of TBI among persons with IDD was, on an average, 1.86 times higher compared to persons with No-IDD with a minimum relative risk of 1.56 in 2009/10 and 2014/15, and a maximum relative risk of 2.34 in 2002/03. As mentioned, within all cohorts, there was a trend of increasing TBI incidence over time. Based on the CIs, results were considered significant for all study years for both the crude and adjusted rates.

Annual incidence and risk ratios for persons who had a TBI prior to being diagnosed with IDD were included for the last three study years. Based on these data, annual incidence is significantly higher in this population compared to all persons with IDD and those without IDD.

The mechanism of injury variable examined falls, motor vehicle collisions, struck by or against an object, and “other” (e.g. unknown or multiple causes). Falls were the leading cause of TBI in 2002/03 and 2016/17, resulting in approximately 45%–50% of TBI cases identified in each cohort in both study years.

DISCUSSION

This population-based cohort study is the first study to quantitatively examine TBI among persons with IDD. The results of this study provide novel data on the risk of TBI among adults with IDD in comparison to adults without IDD. At baseline, persons with IDD were more likely to be male, younger in age, and residing in lower income neighborhoods compared to persons without IDD. Over the 15-year study period, the average adjusted annual incidence of TBI was 2.75 new cases per 1000 among Ontario adults with IDD compared to an average of 1.53 new cases per 1000 among Ontario adults without IDD. Over time, annual incidence of TBI increased in both cohorts; however, the increased risk of TBI among persons with IDD remained significant.

The results of this study showed similar trends in TBI incidence as have been shown in previous research for the general population. Overall, annual incidence in both populations increased gradually over the 15-year period. This finding of increasing TBI incidence is consistent with the majority of existing research that addresses trends in TBI risk over time.^{1,7} This increasing trend in TBI incidence over time may be partly explained by increasing awareness of concussions,¹⁹ which is a common form of TBI, as well as increasing media attention.

This study built upon existing research of TBI incidence and associated characteristics in the general population and contributed new information on TBI incidence and associated characteristics in a vulnerable population. Similar to previous studies,^{1,4,5} there was a noticeable sex difference in the first few study years in both cohorts such that approximately 60%–65% of new TBI cases were among males. Interestingly, this sex difference began to decrease in those without IDD beginning as early as fiscal year 2009/10, and was diminished by 2013/14 and remained so until the end of the study period; the sex difference did remain present among persons with IDD for all study years (Figure 2). This diminished sex difference in the group without IDD is in stark contrast to the majority of other TBI literature; however, a similar trend is seen in self-report studies²⁰ in which the incidence among adult females is rapidly approaching that of

Table 1: Crude and age-/sex-standardized annual incidence (per 1000 persons) of traumatic brain injury (TBI) among Ontario adults with and without intellectual and developmental disabilities (IDD) and risk ratios (RR). (2002/03 to 2016/17)

Year	Cohort	Annual Incidence				Risk Ratio			
		Crude Incidence		Standardized Incidence		Crude Incidence Risk Ratio		Standardized Incidence Risk Ratio	
		per 1000	95% CI ^Φ	per 1000	95% CI ^Φ	RR	95% CI ^Φ	RR	95% CI ^Φ
2002–03	ALL-IDD	2.23	1.68–2.77	2.26	1.71–2.80	2.34	1.81–3.01	2.36	1.83–3.04
	No-IDD	0.95	0.89–1.01	0.96	0.89–1.02				
2003–04	ALL-IDD	2.01	1.51–2.52	2.17	1.65–2.70	2.14	1.65–2.77	2.30	1.78–2.98
	No-IDD	0.94	0.88–1.00	0.94	0.88–1.00				
2004–05	ALL-IDD	1.67	1.22–2.12	1.57	1.13–2.01	1.68	1.27–2.21	1.57	1.19–2.06
	No-IDD	0.99	0.93–1.06	1.00	0.94–1.07				
2005–06	ALL-IDD	1.87	1.40–2.33	1.72	1.28–2.17	1.86	1.44–2.40	1.71	1.32–2.21
	No-IDD	1.01	0.94–1.07	1.01	0.94–1.07				
2006–07	ALL-IDD	2.38	1.87–2.89	2.51	1.99–3.04	2.31	1.84–2.88	2.43	1.94–3.04
	No-IDD	1.03	0.97–1.09	1.03	0.97–1.10				
2007–08	ALL-IDD	2.18	1.71–2.65	2.19	1.71–2.66	1.87	1.49–2.34	1.86	1.48–2.33
	No-IDD	1.17	1.10–1.23	1.18	1.11–1.24				
2008–09	ALL-IDD	2.34	1.86–2.82	2.29	1.82–2.77	1.82	1.47–2.24	1.77	1.43–2.19
	No-IDD	1.29	1.22–1.36	1.29	1.22–1.36				
2009–10	ALL-IDD	2.24	1.79–2.70	2.18	1.73–2.62	1.56	1.27–1.92	1.50	1.21–1.84
	No-IDD	1.43	1.36–1.51	1.45	1.38–1.53				
2010–11	ALL-IDD	2.81	2.32–3.30	2.70	2.22–3.18	1.91	1.59–2.29	1.81	1.51–2.17
	No-IDD	1.47	1.40–1.54	1.49	1.41–1.56				
2011–12	ALL-IDD	3.34	2.82–3.85	3.38	2.86–3.90	2.09	1.78–2.46	2.10	1.78–2.47
	No-IDD	1.59	1.52–1.67	1.61	1.53–1.68				
2012–13	ALL-IDD	2.93	2.46–3.40	2.87	2.41–3.34	1.65	1.39–1.94	1.60	1.36–1.89
	No-IDD	1.78	1.70–1.86	1.79	1.71–1.87				
2013–14	ALL-IDD	3.52	3.02–4.02	3.51	3.01–4.00	1.73	1.49–2.01	1.72	1.48–1.99
	No-IDD	2.03	1.95–2.11	2.04	1.96–2.13				
2014–15	ALL-IDD	3.28	2.81–3.74	3.54	3.06–4.02	1.56	1.34–1.80	1.68	1.44–1.94
	TBI-Prior to IDD*	12.24	5.87–18.61	⊠	N/A	5.76	3.42–9.71	⊠	N/A
	No-IDD	2.10	2.02–2.19	2.11	2.03–2.20	(ref)		(ref)	
2015–16	ALL-IDD	4.08	3.58–4.58	4.07	3.57–4.57	1.73	1.52–1.97	1.72	1.51–1.95
	TBI-Prior to IDD*	13.19	6.96–19.42	⊠	N/A	5.54	3.45–8.90	⊠	N/A
	No-IDD	2.35	2.27–2.44	2.36	2.27–2.45	(ref)		(ref)	
2016–17	ALL-IDD	4.35	3.84–4.85	4.24	3.75–4.74	1.67	1.48–1.88	1.62	1.43–1.82
	TBI-Prior to IDD*	13.45	7.44–19.45	⊠	N/A	5.10	3.26–7.99	⊠	N/A
	No-IDD	2.61	2.51–2.70	2.62	2.53–2.71	(ref)		(ref)	

*: Due to small sample size, data for this population is not available for years prior to 2014/15

⊠: Data not available due to small cohort size

Φ: Confidence Interval

adult males. Hospital data from the United States also reveals evidence of a similar trend beginning in 2009,²¹ however, this report only has data up to 2010. One possible explanation for this disappearing sex difference could be that the study excludes children under 19 years of age, among whom the sex difference tends to be greater.^{1,4,20} Additionally, historically, there has been a tendency to overlook and/or dismiss symptoms in women

because they have often been assumed to be exaggerating symptoms, and thus not taken seriously when describing symptoms of TBI, resulting in misdiagnosis or being told their symptoms are psychosomatic.²² The increasing awareness of concussions may contribute to the disproportionate increase in female TBI cases over time and therefore, diminished sex difference. This hypothesis is supported by one study which

found no significant sex difference in TBI incidence based on self-reports.²⁰ Due to the higher level of patient complexity among patients with IDD,²³ it is plausible that these influences would not result in any change in recognition of female TBI cases among persons with IDD. Although it is not certain why the sex difference for persons without IDD disappears in the later years of this study, this change is not due to any differences in the coding algorithm applied for identifying TBI in either population as the same algorithm was applied to all study populations in all study years. Overall, this indicates that sex distribution of TBI cases is changing among persons without IDD while sex distribution of TBI cases has remained stable among persons with IDD.

In agreement with previous literature,^{1,4,5} the highest proportion of incident TBI cases were among the youngest age group, persons aged 19–29 years. This was true in both persons with IDD and persons without IDD. Also consistent with previous literature,^{1,4} the second highest proportion of TBI cases in the No-IDD group was found among persons aged 70 years and older. In contrast, among persons with IDD, the proportion of incident TBI cases typically decreased with age and was lowest for persons aged 70 years and older. These findings provide evidence that TBI cases among persons with IDD are younger on an average compared to persons without IDD. One possible explanation for this difference in age trends among TBI cases in persons with IDD versus those without IDD could reflect the differences in the general age structure of each population as persons with IDD have a shorter life expectancy.²³

The leading cause of TBI in both cohorts was falls. In both 2002/03 and 2016/17, falls accounted for approximately 50% of all TBI cases in both persons with IDD and those without. This finding is consistent with the existing body of TBI research.^{4,13}

Although this study intended to also analyze the impact of experiencing a TBI prior to receiving a diagnosis of IDD in the IDD population, the ability to do so was limited by the small sample size for this population. Incidence in this population could only be reported for the last three study years in order to minimize the risk of re-identification and comply with institutional privacy regulations. Based on the three study years for which data on this population is included, there is some evidence that having a TBI prior to being diagnosed with IDD significantly increases future TBI risk compared to persons with All-IDD as well as those with No-IDD. However, due to the small population, it was not possible to calculate standardized rates, and it is difficult to say with certainty the true impact of a TBI prior to IDD diagnosis on future TBI risk.

There were certain limitations to the study related to the retrospective nature of the study design. This study relied on the use of administrative data which depends on the accuracy and representativeness of existing data. When identifying persons with IDD, it is possible that some individuals were not identified using the coding algorithm applied to this study resulting in individuals being misclassified as not having IDD. This type of misclassification, however, would result in an underestimation of the true risk ratio for TBI. Since the age, sex, and income distribution of the IDD group is consistent with past reports of this population that included other data sources for identifying IDD,^{15,23,24} the group from the current study is also likely to be representative of persons with IDD in Ontario.

Similarly, with regard to TBI identification, it is possible that individuals may have been misdiagnosed, or there may have been

limitations to the coding algorithm applied in this study, which would result in an under-representation of the true number of incident TBI cases. Many symptoms of TBI, particularly mild TBI such as concussions, are subtle and nonspecific (e.g. nausea, headache) and may not prompt the clinician to inquire about recent trauma resulting in cases being missed or misdiagnosed.⁵ Moreover, some people may not seek medical attention for these kinds of symptoms.⁴ Additionally, due to the lack of consensus on case identification for TBI, this research applied a more conservative case definition that excluded unspecified injury to the head or face, which may contribute to the lower number of TBI identified compared to other literature. It is important to note however that the same coding algorithm was applied to each cohort, so the differences in TBI incidence between cohorts was not due to any inconsistency in the case definition. Additionally, although previous research has found that 70%–90% of TBI are mild TBI such as concussion,^{5,13} the quality of information on TBI severity was not adequate to include in analyses. The present study found that approximately 60% of TBI in 2002/03 were classified as mild in both persons with IDD and those without; however, for 2016/17, more than 70% of cases in both populations were classified as “unknown.”

This study provides a precedent for future detection and surveillance of TBI among persons with IDD. The results of this study provide significant evidence of the importance of examining TBI among persons with IDD. Persons with IDD were found to have a significant increased risk of TBI compared to those without IDD, and added to existing literature by indicating a trend of increasing TBI incidence. As the population of persons with IDD grows, it would be useful to repeat this study to identify if this trend remains, particularly if TBI incidence continues to increase over time.

There is evidence that as many as 95% of injuries, including TBIs, are predictable and preventable.²⁵ Previous studies have already indicated the importance of further examining TBI among persons with IDD,¹² as well as bringing to attention the importance of TBI prevention.⁷ Since the leading cause of TBI is falls, tailoring falls prevention programs to the needs of persons with IDD may be an effective way to mitigate TBI risk. Existing falls prevention programs in some jurisdictions including Ontario are restricted to persons aged 65 and older;²⁶ adjusting this age-restriction to allow younger individuals to participate may be beneficial for persons with IDD who require falls prevention at a younger age.^{10,23} Additionally, further research to identify differences in risk factors for falls among persons with IDD versus those without IDD are needed to provide direction for potentially useful interventions.

Further research should aim to identify additional reasons for increased TBI risk among persons with IDD in order to better address this problem. For instance, it is well established that in the general population, athletes have a higher risk of TBI, especially concussions, versus nonathletes,^{17,27} however, there has been no research on the incidence of head injuries in athletes with IDD. One study did find that among persons with IDD, Special Olympics athletes had 1.35 times increased odds of falling compared to nonathletes.²⁸ This finding was not statistically significant but does suggest that TBI risk might be even higher among athletes with IDD and that falls prevention and efforts to improve balance and coordination are also important in athletes with IDD. Future research should aim to specifically examine the

risk of head injuries, or TBI, among athletes with IDD. Although it is difficult to distinguish using administrative data alone and was not within the scope of this research, prevalence of TBI among persons with IDD would be useful to examine in the future to identify the burden of TBI compared to those without IDD. Additionally, future studies should be conducted to identify other populations at greater risk for TBI as this would help to improve recommendations for effective prevention programs by identifying target populations. Furthermore, developing a validated algorithm for identifying incident cases of TBI from administrative databases would be useful for conducting regular surveillance.

CONCLUSION

The annual incidence of TBI was significantly higher among persons with IDD compared to those without IDD even after adjusting for age and sex, over a 15-year period. These data provide evidence that individuals with IDD have a greater risk of TBI compared to those without IDD regardless of the differences in population age and sex structure. Public health policy development and prevention planning aimed at addressing the high rates and associated costs of TBI should consider targeted interventions for persons with IDD.

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STATEMENT OF AUTHORSHIP

Each of the authors contributed significantly to this paper. KS conceived and designed the work with supervision from RB, ML, and VC. KS performed the data analysis with contribution from HC. All authors contributed to the interpretation of the data. The paper was drafted by KS and revised for important intellectual content by RB, ML, VC, and HC.

DISCLOSURES

The authors have no conflicts of interest to disclose.

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