

BMJ Open Substance-related and addictive disorders among adults with intellectual and developmental disabilities (IDD): an Ontario population cohort study

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ABSTRACT

Objectives: Describe the prevalence of substance-related and addictive disorders (SRAD) in adults with intellectual and developmental disabilities (IDD) and compare the sociodemographic and clinical characteristics of adults with IDD and SRAD to those with IDD or SRAD only.

Design: Population-based cohort study (the Health Care Access Research and Development Disabilities (H-CARDD) cohort).

Setting: All legal residents of Ontario, Canada.

Participants: 66 484 adults, aged 18–64, with IDD identified through linked provincial health and disability income benefits administrative data from fiscal year 2009. 96 589 adults, aged 18–64, with SRAD but without IDD drawn from the provincial health administrative data.

Main outcome measures: Sociodemographic (age group, sex, neighbourhood income quintile, rurality) and clinical (psychiatric and chronic disease diagnoses, morbidity) characteristics.

Results: The prevalence of SRAD among adults with IDD was 6.4%, considerably higher than many previous reports and also higher than found for adults without IDD in Ontario (3.5%). Among those with both IDD and SRAD, the rate of psychiatric comorbidity was 78.8%, and the proportion with high or very high overall morbidity was 59.5%. The most common psychiatric comorbidities were anxiety disorders (67.6%), followed by affective (44.6%), psychotic (35.8%) and personality disorders (23.5%). These adults also tended to be younger and more likely to live in the poorest neighbourhoods compared with adults with IDD but no SRAD and adults with SRAD but no IDD.

Conclusions: SRAD is a significant concern for adults with IDD. It is associated with high rates of psychiatric and other comorbidities, indicating that care coordination and system navigation may be important concerns. Attention should be paid to increasing the recognition of SRAD among individuals with IDD by both healthcare and social service providers and to improving staff skills in successfully engaging those with both IDD and SRAD.

Strengths and limitations of this study

- This is a population-based study which captures individuals receiving and not receiving intellectual and developmental disabilities (IDD)-specific services and allows comparisons with non-IDD groups drawn from the same population.
- Health and disability support data were linked allowing improved identification of individuals with IDD, a group difficult to capture using single-source data.
- Administrative data were not designed with research or clinical priorities in mind meaning that some important questions could not be answered.
- There are few published validation studies for health administrative data and none, to date, for disability support administrative data due, in part, to the very heterogeneous conditions comprising IDD.

INTRODUCTION

Relatively little research has examined substance-related and addictive disorders (SRAD) in adults with intellectual and developmental disabilities (IDD).¹ The prevalence studies that exist have found rates of substance use or abuse ranging between 0.5% and 2.6%, which are lower than rates reported for the general population.^{2–3} Individuals with IDD who use substances are more likely to be younger, male and diagnosed with milder disabilities.^{4–5} They are also at increased risk for negative consequences from substance use (eg, increased risk taking, aggression) and for becoming victims of crime and becoming involved with the justice system.^{4–8} A high percentage (42–54%) are reported to have comorbid psychiatric disorders.^{4–9} These studies, however, are limited by inconsistent definitions, differences in data gathering methods, small sample sizes and

varying inclusion/exclusion criteria¹ leading to a concern that their prevalence rates are underestimates and to calls for good population-based estimates.^{2 4 10 11}

Our aim is to use a large population-based cohort of adults with IDD to describe the prevalence of SRAD and to compare the sociodemographic and clinical characteristics of adults with both IDD and SRAD to other adults from the same population who only have IDD or only have SRAD.

METHODS

Data from the Health Care Access Research and Development Disabilities (H-CARDD) cohort were analysed for this study. This cohort was created by linking Ontario health administrative records (including inpatient, emergency department (ED) and physician contacts) and disability income support administrative data from fiscal 2009. These databases capture all of the healthcare users covered under Ontario's universal healthcare system as well as all recipients of provincial disability income benefits. They were linked using both probabilistic and deterministic methods (through unique encoded identifiers) and analyzed at the Institute for Clinical Evaluative Sciences (ICES); all activities related to cohort creation and this specific study were approved by the Research Ethics Boards at Sunnybrook Hospital and the Centre for Addiction and Mental Health, both in Toronto. The H-CARDD cohort is comprised of 66 484 adults, aged 18–64 years, with a developmental disability (IDD). Our definition of IDD is based on the one used by our provincial government to determine disability benefit eligibility and is consistent with provincial legislation.¹² It includes conditions labelled in other jurisdictions as intellectual or developmental disability. The H-CARDD cohort is, to the best of our knowledge, the largest population-based IDD cohort currently existing. The methods used to create this cohort, along with the list of included diagnostic conditions, are described elsewhere.^{13 14}

We compared three groups: one with both IDD and SRAD (*IDD-plus-SRAD*), one with only IDD (*IDD-only*) and one with only SRAD (*SRAD-only*). To create these three groups, we used the H-CARDD cohort as well as a 20% sample of all Ontario adults who were aged 18–64, eligible for Ontario health benefits, but *not* in the H-CARDD cohort. (The latter group has been used in previous work to provide a comparative context).¹⁵ The presence of SRAD was defined as any healthcare contact within the 2 years prior to fiscal 2009 associated with a psychoactive substance-related or behavioural addiction diagnosis (essentially, F1 or F63.0 International Classification of Diseases (ICD)-10 codes or the ICD-9 or Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV equivalents—for the detailed list, please contact corresponding author).

These three groups were compared on sociodemographic and clinical characteristics. Sociodemographic

variables included age group, sex, rurality and neighbourhood income quintile. The measures of rurality and neighbourhood income were based on Statistics Canada definitions. Urban–rural status was derived from census subdivisions using the Statistical Area Classification of Statistics¹⁶ in which rural represents areas outside of the commuting zones of larger urban centres with a core population of 10 000 or more. For the neighbourhood income measure, Ontario neighbourhoods were grouped in approximately equal-sized quintiles from poorest (quintile 1) to wealthiest (quintile 5) using 2006 census dissemination areas taking into account household size and community of residence.¹⁷

Clinical variables included measures of psychiatric disorder, five chronic physical illnesses and a comorbidity proxy. Psychiatric disorder was defined using the available diagnostic information in the health administrative data. Since the coding system varied by health data source (ICD-10 for ED and acute hospital data, broad ICD-8 categories for the physician visit data, and DSM-4 for psychiatric hospital data), our analyses used broader diagnostic categories.

The choice of the five chronic diseases was dictated by the existence of algorithms previously validated for the health administrative data we used. These were diabetes,¹⁸ hypertension,¹⁹ chronic obstructive pulmonary disorder (COPD),²⁰ asthma²¹ and congestive heart failure.²² Comorbidity was measured using the John Hopkins Adjusted Clinical Groups (ACGs) Case-Mix System as a proxy.²³ This variable, which captures expected use of healthcare resources, has six categories (non-user, healthy user, low, moderate, high and very high). For our analyses, we examined the percentage with high or very high morbidity.

Sociodemographic characteristics were reported as crude percentages while the clinical characteristic results were adjusted for age and sex using the age–sex composition of our group of interest (*IDD-plus-SRAD*) as the standard. We used Cohen's *d* (effect size) to determine whether the observed and adjusted differences were meaningful. This statistic is independent of sample size, useful in our case because the very large numbers inflate statistical significance. It is used to represent the magnitude of difference between two groups, where 0.2, 0.5 and 0.8 are often interpreted as reflecting small, medium and large effect sizes, respectively.²⁴ SAS V.9.4 (SAS Institute Inc. Base SAS 9.4. procedures guide: Statistical procedures. 2013) was used to generate descriptive frequencies and Wilson's²⁵ web-based calculator to generate logit effect sizes and CIs for binary proportions. To determine meaningfulness, we used a 0.2 cut-off (equivalent to a small effect size) plus the requirement that the absolute value of the 95% CI not to go below 0.2.

RESULTS

There were 4220 individuals in the H-CARDD cohort who met our definition of SRAD. This is equivalent to a

prevalence rate of 6.4%. Among adults without IDD, the prevalence of SRAD was 3.5%.

Table 1 compares the sociodemographic characteristics of the three groups. In terms of age, sex and rurality, there were no remarkable differences between the two *IDD* groups ('A vs B' column), and only one small age group difference with the two *IDD* groups being more likely to be in the youngest age group compared with the *SRAD-only* adults (both effect sizes=0.41).

In terms of socioeconomic status (SES), over 40% of the *IDD-plus-SRAD* group lived in the poorest neighbourhood quintile compared with <30% for *IDD-only* and *SRAD-only* adults (effect sizes=0.2–0.4). The *IDD-plus-SRAD* group was also less likely to live in the two wealthiest neighbourhood quintiles, particularly compared with the *SRAD-only* group (effect sizes=–0.29 and –0.30). With the exception of the poorest quintile, there were no meaningful differences between the *IDD-only* and *SRAD-only* groups based on our previously described criteria.

Larger differences were evident when the psychiatric comorbidities of the three groups were examined. In terms of unadjusted rates (not shown), over three-quarters of the adults with *IDD-plus-SRAD* (78.8%) had a concurrent psychiatric disorder compared with the *IDD-only* and *SRAD-only* groups (41.4% and 51.1%, respectively). The *IDD-plus-SRAD* adults also consistently had the highest prevalence rates when both broad categories and specific psychiatric diagnoses were considered. The most common categories were the anxiety disorders (67.6%), followed by affective illnesses (44.6%), and psychotic disorders (35.8%). In terms of more specific diagnoses, 35.2% had a depressive disorder, 30.5% a schizophrenia/schizophreniform/schizoaffective disorder, 25.2% a bipolar disorder and 23.5% a personality disorder.

Adjusting these prevalence rates (and the rates for chronic illness and morbidity) by age and sex resulted in only minor changes. For example, the overall prevalence for any psychiatric disorder changed from 41.4% to 41.0% and from 51.1% to 50.6% for the *IDD-only* and *SRAD-only* groups, respectively.

Comparison of the adjusted rates (table 2) showed that the three groups differed from each other across all of our measures of psychiatric comorbidity except one (the rates of bipolar disorder for the two single-condition groups). The largest differences were between the two *IDD* groups: of the nine comparisons in column 'A vs B', only the 'other' comparison had an effect size below 0.8. The *IDD-plus-SRAD* also differed from the *SRAD-only* group with all effect sizes in the medium-to-large range. Differences between the two single-condition groups were less marked with all effect sizes below the medium (0.5) threshold. With the exception of the psychotic and 'other' categories, the *IDD-only* adults had the lowest adjusted rates of psychiatric comorbidity of the three groups.

Similar but less marked patterns were found when the age–sex-adjusted rates of chronic illness and morbidity were examined (table 3). As with psychiatric

Table 1 Sociodemographic characteristics

	A IDD-plus-SRAD N=4220	B IDD-only N=62 264	C SRAD-only N=96 589	Cohen's d* (95% CI)		
				A vs B	A vs C	B vs C
Age (%)						
18–24 years	23.6	24.1	12.9	–0.02 (–0.06 to 0.03)	0.41 (0.36 to 0.45)	0.41 (0.41 to 0.44)
25–34 years	22.6	20.0	20.2	0.09 (0.04 to 0.13)	0.08 (0.04 to 0.12)	–0.01 (–0.02 to 0.01)
35–44 years	19.5	20.4	23.0	–0.03 (–0.07 to 0.01)	–0.12 (–0.16 to –0.07)	–0.08 (–0.10 to –0.07)
45–54 years	23.2	22.3	27.8	0.03 (–0.01 to 0.07)	–0.13 (–0.17 to –0.09)	–0.16 (–0.18 to 0.15)
55–64 years	11.0	13.3	16.1	–0.12 (–0.17 to 0.06)	–0.24 (–0.30 to –0.19)	–0.12 (–0.14 to –0.11)
Male (%)	64.4	56.8	58.8	0.18 (0.14 to 0.21)	0.13 (0.10 to 0.17)	–0.05 (–0.06 to –0.03)
Rural (%)	13.4	15.9	13.4	–0.11 (–0.16 to –0.06)	0 (–0.05 to 0.05)	0.11 (0.09 to 0.13)
Neighbourhood income quintile (%)						
1 (lowest)	40.6	29.3	25.6	0.28 (0.24 to 0.31)	0.38 (0.34 to 0.41)	0.10 (0.09 to 0.12)
2	22.3	21.3	21.2	0.03 (–0.01 to 0.07)	0.04 (–0.01 to 0.08)	0.00 (–0.01 to 0.02)
3	14.9	17.6	19.0	–0.11 (–0.16 to –0.06)	–0.16 (–0.21 to –0.11)	–0.05 (–0.07 to –0.04)
4	11.2	16.3	17.9	–0.24 (–0.29 to –0.18)	–0.30 (–0.36 to –0.25)	–0.06 (–0.08 to –0.05)
5 (highest)	9.5	14.2	15.1	–0.25 (–0.31 to –0.19)	–0.29 (–0.35 to –0.23)	–0.04 (–0.06 to –0.02)

*Cells with effect sizes ≥ 0.2 and 95% CIs which do not go below 0.2 are in bold.

IDD, intellectual and developmental disabilities; SRAD, substance-related and addictive disorders.

Table 2 Age-adjusted and sex-adjusted clinical characteristics: psychiatric disorders

	A <i>IDD-plus-SRAD</i> N=4220	B <i>IDD-only</i> N=62 264	C <i>SRAD-only</i> N=96 589	Cohen's d* (95% CI)		
				A vs B	A vs C	B vs C
Psychiatric disorders (excluding SRAD)						
ANY	78.8	41.0	50.6	0.92 (0.88 to 0.97)	0.71 (0.67 to 0.75)	-0.21 (-0.23 to -0.20)
Psychotic	35.8	9.8	5.8	0.90 (0.86 to 0.94)	1.21 (1.18 to 1.25)	0.31 (0.29 to 0.33)
Schizophrenia	30.5	8.5	4.1	0.86 (0.82 to 0.90)	1.28 (1.24 to 1.32)	0.43 (0.40 to 0.45)
Affective	44.6	10.5	18.0	1.06 (1.03 to 1.10)	0.72 (0.68 to 0.75)	-0.35 (-0.36 to -0.33)
Depressive	35.2	7.5	14.8	1.05 (1.01 to 1.09)	0.63 (0.59 to 0.66)	-0.42 (-0.44 to -0.40)
Bipolar	25.2	4.6	6.4	1.07 (1.03 to 1.12)	0.88 (0.84 to 0.92)	-0.19 (-0.22 to -0.17)
Anxiety	67.6	29.4	43.3	0.89 (0.85 to 0.93)	0.55 (0.52 to 0.59)	-0.33 (-0.35 to -0.32)
Personality	23.5	3.3	4.9	1.21 (1.17 to 1.26)	0.98 (0.94 to 1.03)	-0.23 (-0.26 to -0.20)
Other	13.1	7.5	4.8	0.34 (0.29 to 0.39)	0.60 (0.55 to 0.66)	0.26 (0.24 to 0.29)

*Cells with effect sizes ≥ 0.2 and 95% CIs which do not go below 0.2 are in bold.

IDD, intellectual and developmental disabilities; SRAD, substance-related and addictive disorders.

Table 3 Age-adjusted and sex-adjusted clinical characteristics: chronic physical illness and overall morbidity

	A <i>IDD-plus-SRAD</i> N=4220	B <i>IDD-non-SRAD</i> N=62 264	C <i>SRAD-non-DD</i> N=96 589	Cohen's d* (95% CI)		
				A vs B	A vs C	B vs C
Chronic physical illness						
Diabetes	12.6	9.8	6.5	0.16 (0.10 to 0.21)	0.40 (0.35 to 0.45)	0.25 (0.23 to 0.27)
Hypertension	15.3	13.8	13.2	0.07 (0.02 to 0.11)	0.09 (0.05 to 0.14)	0.03 (0.01 to 0.04)
COPD	13.6	5.2	8.5	0.58 (0.53 to 0.63)	0.29 (0.24 to 0.34)	-0.29 (-0.31 to -0.27)
Asthma	27.3	16.5	18.0	0.35 (0.31 to 0.39)	0.30 (0.26 to 0.33)	-0.06 (-0.07 to -0.04)
Congestive heart failure	2.0	1.0	0.7	0.39 (0.26 to 0.51)	0.59 (0.46 to 0.71)	0.20 (0.14 to 0.26)
Morbidity						
Per cent of high/very high morbidity	59.5	21.6	43.2	00.92 (0.89 to 0.96)	0.36 (0.33 to 0.40)	-0.56 (-0.57 to -0.55)

*Cells with effect sizes ≥ 0.2 and 95% CIs which do not go below 0.2 are in bold.

COPD, chronic obstructive pulmonary disorder; IDD, intellectual and developmental disabilities; SRAD, substance-related and addictive disorders.

comorbidity, adults with *IDD-plus-SRAD* consistently had the highest disease and morbidity rates of the three groups. The most common chronic illness in this group was asthma (27.3%) followed by hypertension, COPD and diabetes (12.6–15.3%). When the groups were compared, both *IDD* groups had higher rates of diabetes than the *SRAD-only* group with the difference between the *IDD-plus-SRAD* and *SRAD-only* groups being particularly large (12.6% vs 6.5%, effect size=1.66). No difference was found between the *IDD-only* and *SRAD-only* groups for asthma, but both showed small differences compared with the *IDD-plus-SRAD* group (effect sizes=0.3–0.35). All three groups showed small differences from each other for COPD and congestive heart failure but no differences for hypertension. In terms of high or very high morbidity, the largest difference was between the two *IDD* groups (59.5% vs 21.6%, effect size=0.92) with the other morbidity comparisons falling into the small and moderate effect size ranges.

DISCUSSION

Principal findings

The prevalence of SRAD among adults with IDD was 6.4%, compared with 3.5% in those without IDD. Individuals with both IDD and SRAD had the highest rates of overall morbidity (78.8%, psychiatric comorbidity; 59.5%, high or very high morbidity) and of specific illnesses. The most common psychiatric comorbidities were anxiety disorders (67.6%), followed by affective (44.6%), psychotic (35.8%) and personality disorders (23.5%) while the most common chronic diseases were asthma (27.3%), hypertension (15.3%), COPD (13.6%) and diabetes (12.6%). They also tended to be younger and more likely to live in the poorest neighbourhoods compared with adults with *IDD-only* or *SRAD-only*.

Study strengths and weaknesses

Our work combines several strengths when compared with other reported studies. The H-CARDD cohort is based on data which capture nearly the entire population of a single geopolitical jurisdiction. It includes individuals receiving IDD-specific social services as well as those who have only accessed health services. As such, it avoids some of the biases inherent in analysing smaller clinical samples. It also allows comparisons to groups drawn from the same population and using consistent operational definitions. These provide more detail than previous reports on how the combination of *IDD* and *SRAD* differs from either condition alone. Finally, the use of linked data provides more comprehensive coverage of the IDD population compared with studies using single-source data.^{13 26}

Balancing these strengths are some important limitations. First, like many other studies, our definition of *IDD* has not been externally validated, due in part to the heterogeneous group of conditions classified as *IDD*. There are few published validation studies of

administrative data for this population. Thus far, validation studies for health administrative data exist for autism spectrum disorders^{27–29} and Down syndrome.³⁰ We have found no validity research for either social services or disability support administrative data. Second, administrative data are not usually collected to serve research or even clinical purposes. Consequently, important variables such as illness severity, type of addiction, the type of care delivered, poverty or ethnicity are not typically captured, and thus important questions such as what is the quality and appropriateness of care or the effect of social factors cannot be answered. Third, despite using linked data sources, it is likely that some people with IDD or with addictions were missed.²⁶ The most likely gaps are individuals who were diagnosed with IDD as children or adolescents but who were not recorded as having IDD in adulthood in either the health or disability income support data.¹³ Finally, while a strength of this study is that it captures an entire geopolitical population, the results may not be generalisable to other jurisdictions that have very different health and social service systems or IDD populations.

Important differences in results

Our prevalence for SRAD (6.4%) is considerably higher than previously reported rates.¹ It is also higher than the prevalence we report for adults without *IDD* (3.5%) or what has been found in the Canadian general population (4.4%).³¹ The mostly likely explanation for these differences is our use of linked, population-based data sources which may have captured a larger proportion of individuals with milder forms of *IDD* who are living in the community and not necessarily accessing *IDD*-specific supports.^{11 26} Researchers have suggested that this group is at greater risk for exposure to substances and the risk factors that support substance use and abuse.^{1 4 5}

In addition, we report a prevalence of 79% for psychiatric illnesses among adults with the combination of *IDD* and *SRAD* which is higher than the 42–54% previously reported.^{1 4} A closer look at other population-based studies does not, unfortunately, provide definitive evidence on whether our higher prevalence is an overestimate, an accurate estimate (possibly because of our use of linked data) and/or a function of the definitions and methods we used. Cooper *et al*'s² study, which reported a prevalence of 41% with 'mental ill health of any type' (p. 30), used a combination of disability support records and detailed clinical assessments to define their study cohort of adults with intellectual disabilities. However, they did not look at the prevalence of mental ill health in the subset with comorbid *SRAD*, and it is also unclear what the impact would be of their case ascertainment methods versus ours. To the best of our knowledge, Slayter's⁹ study is the only population-based study to examine rates of psychiatric comorbidity among the subset with an addiction. Their case ascertainment is more similar to ours than the one used by Cooper *et al*, and they report a prevalence of 54% among US Medicaid recipients. However, their study

differs from ours in two ways: first, they only assessed 'serious mental illness' (p.53); second, they only looked at *intellectual disability* (ID; (mental retardation). It seems reasonable that our examination of *all* (and not just serious) psychiatric illnesses in a population which included both *ID* and *development disability* would yield a higher prevalence rate, but what the true magnitude of that rate should be is not clear.

Like other studies, we found that the SRAD group is younger and male.^{1 3} We did not find any other studies about SES although it has been suggested that living in poverty puts individuals with *IDD* at risk for substance abuse.¹ Finally, while it has been suggested that substance abuse impacts the physical health of individuals with *IDD*,¹ ours is the first study to describe this association at a population level and also to compare it with individuals using substances but who do not have *IDD*.

Implications

Our findings support those researchers who have identified SRAD as a significant problem in this population.^{4 11 26} More specifically, our results suggest that within the already complex *IDD* population, *SRAD* is a marker for even more complex, serious conditions as well as for a need to attend closely to engagement, intervention and, in particular, cross-sector care coordination.³² Other researchers have commented on the need for staff training (about *IDD* for addictions services staff and about *SRAD* for providers of *IDD*-specific care).¹ Services and supports that prevent, identify, treat and manage the significant mental health and addiction problems of adults with *IDD* need to be developed and integrated into their programmes of care. In addition, the need to link with social services because of risk factors associated with poverty and also the increased risk of legal involvement associated with *SRAD* have been noted.^{1 3 4} Finally, navigational supports are critical because of the increased information processing demands on the person with *IDD* and their support system. These supports would serve as a starting point for coordinating across the health, mental health, housing and public health services required to adequately meet the complex needs of persons with *IDD* and addictions. To date, research providing evidence about what strategies improve engagement, intervention and system coordination for this population is still in its infancy, and our findings emphasise the need to continue the pursuit of this kind of work.

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