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Substance-related and addictive disorders among adults with intellectual and developmental disabilities (IDD): An Ontario population-based 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 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 to 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 health care 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 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 intellectual and developmental disabilities, 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), reflecting the belief that these individuals do not have access to drugs and alcohol.(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 (e.g., increased risk taking, aggression) and for becoming victims of crime and becoming involved with the justice system. (4,6–8) 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 criteria(1) leading to a concern that their prevalence rates are underestimates and to calls for good population-based estimates.(2,4,10)

Methods

Data from the Health Care Access Research and Development Disabilities (H-CARDD) cohort were analyzed for this study. This cohort was created by linking Ontario health administrative records (including inpatient, emergency department, and physician contacts) and disability income support administrative data from fiscal 2009. These databases capture all of the health care users covered under Ontario's universal health care system as well as all recipients of provincial disability income benefits. The H-CARDD cohort is comprised of 66,484 adults, aged 18-64 years old, 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.(11) It includes conditions labeled in other jurisdictions as intellectual or developmental disability. The H-CARDD cohort is, to 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.(12,13)

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).(14) The presence of SRAD was defined as any health care contact within the two years prior to fiscal 2009 associated with a psychoactive substance-related or behavioural addiction diagnosis (essentially, F1 or F63.0 ICD-10 codes or the ICD-9 or 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 neighborhood income were based on Statistics Canada definitions. Urban-rural status was derived from census subdivisions using the Statistical Area Classification of Statistics(15) 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.(16)

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. Because 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,(17) hypertension,(18) chronic obstructive pulmonary disorder (COPD),(19) asthma,(20) and congestive heart failure.(21) Comorbidity was measured using the John Hopkins Adjusted Clinical Groups (ACGs) Case-Mix System as a proxy.(22) This variable, which captures expected use of health care 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.(23) SAS 9.4(24) was used to generate descriptive frequencies and Wilson's web-based calculator(25) to generate logit effect sizes and confidence intervals for binary proportions.

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 percent.

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 two small age group differences (effect sizes ≈ 0.2-0.4) between the two ***IDD***

groups vs. the ***SRAD-only*** adults. Both ***IDD*** groups were more likely to be in the youngest age group compared to the ***SRAD-only*** adults (effect sizes = 0.41, 0.42). In addition the ***IDD-plus SRAD*** group was less likely to be in the oldest age group compared to the ***SRAD-only*** adults ('A vs C' column, effect size = -0.24).

Table 1: Sociodemographic characteristics

	A DD-Plus-SRAD N = 4220	**B** DD-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	0.01 (-0.06, 0.03)	0.41 (0.36, 0.45)	0.42 (0.10, 0.74)
25-34 years	22.6	20.0	20.2	0.09 (0.04, 0.13)	0.08 (0.04, 0.12)	-0.01 (-0.35, 0.34)
35-44 years	19.5	20.4	23.0	-0.03 (-0.07, 0.01)	-0.12 (-0.16, 0.07)	-0.08 (-0.43, 0.26)
45-54 years	23.2	22.3	27.8	0.03 (-0.01, 0.07)	-0.13 (-0.17, -0.09)	-0.16 (-0.49, 0.17)
55-64 years	11.0	13.3	16.1	-0.02 (-0.07, 0.04)	-0.24 (-0.30, -0.19)	-0.12 (-0.53, 0.28)
% MALE	64.4	56.8	58.8	0.18 (0.14, 0.21)	0.13 (0.10, 0.17)	-0.05 (-0.32, 0.23)
% RURAL	13.4	15.9	13.4	-0.11 (-0.16, -0.06)	0 (-0.05, 0.05)	0.11 (-0.27, 0.49)
NEIGHBOURHOOD INCOME QUINTILE						
1 (lowest)	40.6	29.3	25.6	0.28 (0.24, 0.31)	0.38 (0.34, 0.41)	0.10 (0.09, 0.12)
2	22.3	21.3	21.2	0.03 (-0.01, 0.07)	0.04 (-0.01, 0.08)	0.00 (-0.01, 0.02)
3	14.9	17.6	19.0	-0.11 (-0.16, -0.06)	-0.16 (-0.21, -0.11)	-0.05 (-0.07, -0.04)
4	11.2	16.3	17.9	-0.24 (-0.29, -0.18)	-0.30 (-0.36, -0.25)	-0.06 (-0.08, -0.05)
5 (highest)	9.5	14.2	15.1	-0.25 (-0.31, -0.19)	-0.28 (-0.34, -0.22)	-0.04 (-0.06, -0.02)

* Cells with effect sizes >= 0.2 and 95% C.I.s which do not go below 0.2 are shaded in grey

In terms of socioeconomic status, over forty percent of the ***IDD-plus SRAD*** group lived in the poorest neighbourhood quintile compared to less than 30% for ***IDD-only*** and ***SRAD-only*** adults (effect sizes = 0.2-0.4). The ***IDD-plus-SRAD*** was also comparatively less likely to live in the two wealthiest neighbourhood quintiles. There were no discernible differences between the ***IDD-only*** and ***SRAD-only*** groups (all effect sizes ≤ 0.1).

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 to 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.

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

	A DD-Plus-SRAD N = 4220	**B** DD-Only N = 62,264	**C** SRAD-only 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. 0.97)	0.71 (0.67, 0.75)	-0.21 (-0.23, -0.20)
Psychotic	35.8	9.8	5.8	0.90 (0.86. 0.94)	1.21 (1.18, 1.25)	0.31 (0.29, 0.33)

Schizophrenia	30.5	8.5	4.1	0.86 (0.82, 0.90)	1.28 (1.24, 1.32)	0.43 (0.43, 0.46)
Affective	44.6	10.5	18.0	1.06 (1.03, 1.10)	0.72 (0.68, 0.75)	-0.35 (-0.36, -0.33)
Depressive	35.2	7.5	14.8	1.05 (1.01, 1.09)	0.63 (0.59, 0.66)	-0.42 (-0.44, -0.40)
Bipolar	25.2	4.6	6.4	1.07 (1.03. 1.11)	0.88 (0.84, 0.92)	-0.19 (-0.22, -0.17)
Anxiety	67.6	29.4	43.3	0.89 (0.85, 0.93)	0.55 (0.52, 0.59)	-0.33 (-0.35, -0.32)
Personality	23.5	3.3	4.9	1.21 (1.17, 1.26)	0.98 (0.94, 1.03)	-0.23 (-0.26, -0.20)
Other	13.1	7.5	4.8	0.34 (0.29, 0.39)	0.60 (0.55, 0.66)	0.26 (0.24, 0.29)

* Cells with effect sizes >= 0.2 and 95% C.I.s which do not go below 0.2 are shaded in grey

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 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 to 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 to 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.

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

	A DD-plus SRAD N = 4220	**B** DD-non-SRAD N = 62,264	**C** SRAD-non-DD 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, 0.21)	1.66 (1.60, 1.73)	0.25 (0.23, 0.27)
Hypertension	15.3	13.8	13.2	0.07 (0.02, 0.11)	0.09 (0.05, 0.14)	0.03 (0.01, 0.04)

COPD	13.6	5.2	8.5	0.58 (0.53, 0.63)	0.58 (0.53, 0.63)	-0.29 (-0.31, -0.26)
Asthma	27.3	16.5	18.0	0.35 (0.31, 0.39)	0.30 (0.26, 0.33)	-0.06 (-0.07, -0.04)
Congestive Heart Failure	2.0	1.0	0.7	0.39 (0.26, 0.51)	0.59 (0.46, 0.71)	0.20 (0.14, 026)
MORBIDITY						
% high/very high morbidity	59.5	21.6	43.2	0.92 (0.89, 0.96)	0.36 (0.33, 0.40)	-0.56 (-0.57, -0.55)

Discussion

Principal findings. The prevalence of SRAD among adults with IDD was 6.4%, compared to 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 to adults with ***IDD-only*** or ***SRAD-only***.

Study strengths and weaknesses. Our work combines several strengths when compared to other reported studies. The H-CARDD cohort is based on data which captures nearly the entire population of a single geo-political 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 analyzing 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 to studies using single-source data.(12)

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(26–28) and Down Syndrome.(29) We have found no validity research for either social services or disability support administrative data. Second, administrative data is not usually collected to serve research or even clinical purposes. Consequently, important variables such as illness severity, 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 were missed. 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.(12)

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%).(30) 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. 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.'s study, (2) 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 our knowledge, Slayer's study (9) 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 and colleagues, 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 ***ID*** (mental retardation). It seems reasonable that our examination of all psychiatric illnesses in a population which included both ***ID*** and ***DD*** 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) 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.(31) 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) 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. To date, research providing evidence about what strategies improve engagement, intervention, and system coordination for this population is still in its infancy.

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Compelling interests

There are no competing interests on the part of any of the authors of this manuscript.

Author contributions

E. Lin, R. Balogh, and Y. Lunsky were the primary creators of the concept and design of this study. The analytic approach was created by E. Lin, R. Balogh, and A. Wilton and carried out by A. Wilton. E. Lin was responsible for creating the first draft and integrating all co-author input. All co-authors were involved in the acquisition of the data, contributed substantively to the interpretation of the results and to draft revisions, and have approved the final version of the manuscript.

Data Sharing

No additional data available.

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

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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 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 to 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 health care 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 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 intellectual and developmental disabilities, 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 (e.g., increased risk taking, aggression) and for becoming victims of crime and becoming involved with the justice system.(4,6–8) 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 criteria(1) 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 analyzed for this study. This cohort was created by linking Ontario health administrative records (including inpatient, emergency department, and physician contacts) and disability income support administrative data from fiscal 2009. These databases capture all of the health care users covered under Ontario's universal health care system as well as all recipients of provincial disability income benefits. The H-CARDD cohort is comprised of 66,484 adults, aged 18-64 years old, 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 labeled in other jurisdictions as intellectual or developmental disability. The H-CARDD cohort is, to 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 health care contact within the two years prior to fiscal 2009 associated with a psychoactive substance-related or behavioural addiction diagnosis (essentially, F1 or F63.0 ICD-

10 codes or the ICD-9 or 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 neighborhood income were based on Statistics Canada definitions. Urban-rural status was derived from census subdivisions using the Statistical Area Classification of Statistics(16) 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. Because 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) asthma,(21) 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 health care 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 9.4(25) was used to generate descriptive frequencies and Wilson's web-based calculator(26) to generate logit effect sizes and confidence intervals 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% confidence interval not 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 percent.

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 to the ***SRAD-only*** adults (both effect sizes = 0.41).

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, 0.03)	0.41 (0.36, 0.45)	0.41 (0.41, 0.44)
25-34 years	22.6	20.0	20.2	0.09 (0.04, 0.13)	0.08 (0.04, 0.12)	-0.01 (-0.02, 0.01)
35-44 years	19.5	20.4	23.0	-0.03 (-0.07, 0.01)	-0.12 (-0.16, -0.07)	-0.08 (-0.10, -0.07)
45-54 years	23.2	22.3	27.8	0.03 (-0.01, 0.07)	-0.13 (-0.17, -0.09)	-0.16 (-0.18, 0.15)
55-64 years	11.0	13.3	16.1	-0.12 (-0.17, 0.06)	-0.24 (-0.30, -0.19)	-0.12 (-0.14, -0.11)
% MALE	64.4	56.8	58.8	0.18 (0.14, 0.21)	0.13 (0.10, 0.17)	-0.05 (-0.06, -0.03)
% RURAL	13.4	15.9	13.4	-0.11 (-0.16, -0.06)	0 (-0.05, 0.05)	0.11 (0.09, 0.13)
NEIGHBOURHOOD INCOME QUINTILE						
1 (lowest)	40.6	29.3	25.6	0.28 (0.24, 0.31)	0.38 (0.34, 0.41)	0.10 (0.09, 0.12)
2	22.3	21.3	21.2	0.03 (-0.01, 0.07)	0.04 (-0.01, 0.08)	0.00 (-0.01, 0.02)
3	14.9	17.6	19.0	-0.11 (-0.16, -0.06)	-0.16 (-0.21, -0.11)	-0.05 (-0.07, -0.04)
4	11.2	16.3	17.9	-0.24 (-0.29, -0.18)	-0.30 (-0.36, -0.25)	-0.06 (-0.08, -0.05)
5 (highest)	9.5	14.2	15.1	-0.25 (-0.31, -0.19)	-0.29 (-0.35, -0.23)	-0.04 (-0.06, -0.02)

* Cells with effect sizes >= 0.2 and 95% C.I.s which do not go below 0.2 are shaded in grey

In terms of socioeconomic status, over forty percent of the ***IDD-plus SRAD*** group lived in the poorest neighbourhood quintile compared to less than 30% for ***IDD-only*** and ***SRAD-only*** adults (effect sizes = 0.2-0.4). The ***IDD-plus-SRAD*** was also less likely to live in the two wealthiest neighbourhood quintiles, particularly compared to the SRAD-only group (effect sizes = -.29 and -.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 to 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.

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

	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
PSYCHIATRIC DISORDERS (excluding SRAD)						
ANY	78.8	41.0	50.6	0.92 (0.88. 0.97)	0.71 (0.67, 0.75)	-0.21 (-0.23, -0.20)
Psychotic	35.8	9.8	5.8	0.90 (0.86. 0.94)	1.21 (1.18, 1.25)	0.31 (0.29, 0.33)
Schizophrenia	30.5	8.5	4.1	0.86 (0.82, 0.90)	1.28 (1.24, 1.32)	0.43 (0.40, 0.45)
Affective	44.6	10.5	18.0	1.06 (1.03, 1.10)	0.72 (0.68, 0.75)	-0.35 (-0.36, -0.33)
Depressive	35.2	7.5	14.8	1.05 (1.01, 1.09)	0.63 (0.59, 0.66)	-0.42 (-0.44, -0.40)
Bipolar	25.2	4.6	6.4	1.07 (1.03. 1.12)	0.88 (0.84, 0.92)	-0.19 (-0.22, -0.17)
Anxiety	67.6	29.4	43.3	0.89 (0.85, 0.93)	0.55 (0.52, 0.59)	-0.33 (-0.35, -0.32)
Personality	23.5	3.3	4.9	1.21 (1.17, 1.26)	0.98 (0.94, 1.03)	-0.23 (-0.26, -0.20)
Other	13.1	7.5	4.8	0.34 (0.29, 0.39)	0.60 (0.55, 0.66)	0.26 (0.24, 0.29)

* Cells with effect sizes >= 0.2 and 95% C.I.s which do not go below 0.2 are shaded in grey

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 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 to 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 to 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.

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

	A IDD-plus SRAD N = 4220	B IDD-non-SRAD N = 62,264	C SRAD-non-DD 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, 0.21)	0.40 (0.35, 0.45)	0.25 (0.23, 0.27)
Hypertension	15.3	13.8	13.2	0.07 (0.02, 0.11)	0.09 (0.05, 0.14)	0.03 (0.01, 0.04)
COPD	13.6	5.2	8.5	0.58 (0.53, 0.63)	0.29 (0.24, 0.34)	-0.29 (-0.31, -0.27)
Asthma	27.3	16.5	18.0	0.35 (0.31, 0.39)	0.30 (0.26, 0.33)	-0.06 (-0.07, -0.04)
Congestive Heart Failure	2.0	1.0	0.7	0.39 (0.26, 0.51)	0.59 (0.46, 0.71)	0.20 (0.14, 026)
MORBIDITY						
% high/very high morbidity	59.5	21.6	43.2	0.92 (0.89, 0.96)	0.36 (0.33, 0.40)	-0.56 (-0.57, -0.55)

Discussion

Principal findings. The prevalence of SRAD among adults with IDD was 6.4%, compared to 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 to adults with ***IDD-only*** or ***SRAD-only***.

Study strengths and weaknesses. Our work combines several strengths when compared to other reported studies. The H-CARDD cohort is based on data which captures nearly the entire population of a single geo-political 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 analyzing 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 to studies using single-source data.(13, 27)

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(28–30) and Down Syndrome.(31) We have found no validity research for either social services or disability support administrative data. Second, administrative data is 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 (27). 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 generalizable 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%).(32) 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, 27). 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.'s study, (2) 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 our knowledge, Slayer's study (9) 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 and colleagues, 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 ***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 ***DD*** 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, 27) 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.(33) 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 addictions problems of adults with IDD need to be developed and integrated into their programs 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 emphasize the need to continue the pursuit of this kind of work.

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Compelling interests

There are no competing interests on the part of any of the authors of this manuscript.

Author contributions

E. Lin, R. Balogh, and Y. Lunsky were the primary creators of the concept and design of this study. The analytic approach was created by E. Lin, R. Balogh, and A. Wilton and carried out by A. Wilton. E. Lin was responsible for creating the first draft and integrating all co-author input. All co-authors were involved in the acquisition of the data, contributed substantively to the interpretation of the results and to draft revisions, and have approved the final version of the manuscript.

Data sharing statement

No additional data are available.

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STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract **page 1**
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found **pages 2-3**
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported **Introduction (page 4)**
Objectives	3	State specific objectives, including any prespecified hypotheses **Introduction (page 4)**
Methods		
Study design	4	Present key elements of study design early in the paper **Methods (pages 4-5)**
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection **Methods (paragraph 1)**
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up **Methods (paragraphs 1 and 2)**
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed **(n/a)**
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable **Methods (pages 4-5)**
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group **Methods (pages 4-5)**
Bias	9	Describe any efforts to address potential sources of bias **Methods (last paragraph)**
Study size	10	Explain how the study size was arrived at **(n/a: population-based cohort)**
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why **Methods (pages 4-5)**
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding **Methods (last paragraph)**
		(*b*) Describe any methods used to examine subgroups and interactions **(n/a)**
		(*c*) Explain how missing data were addressed **(n/a)**
		(*d*) If applicable, explain how loss to follow-up was addressed **(n/a)**
		(*e*) Describe any sensitivity analyses **(n/a)**
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed **(n/a)**
		(b) Give reasons for non-participation at each stage **(n/a)**

		(c) Consider use of a flow diagram **(n/a)**
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders **Table 1**
		(b) Indicate number of participants with missing data for each variable of interest **(n/a)**
		(c) Summarise follow-up time (eg, average and total amount) **(n/a)**
Outcome data	15*	Report numbers of outcome events or summary measures over time **Tables 2 and 3**
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included **Tables 2 and 3**
		(*b*) Report category boundaries when continuous variables were categorized **Methods (paragraph 3)**
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period **(n/a)**
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses **(n/a)**
Discussion		
Key results	18	Summarise key results with reference to study objectives **Discussion (paragraph 1)**
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias **Discussion (paragraphs 2 and 3)**
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence **Discussion (paragraphs 4, 5, and 6)**
Generalisability	21	Discuss the generalisability (external validity) of the study results **Discussion (paragraph 3)**
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based **Funding paragraph (page 12)**

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.