Using national surveys for mental health surveillance of individuals with intellectual disabilities in Canada

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Abstract

Introduction: Individuals with intellectual disabilities have a higher prevalence of health problems, including psychiatric and behavioural conditions, than the general population. However, there is little population-based information in Canada about individuals with a dual diagnosis of psychiatric disorder and intellectual impairment. The aim of this study was to determine whether the 2005 Canadian Community Health Survey (CCHS) and the 2006 Participation and Activity Limitation Survey (PALS) could be used to estimate the prevalence of dual diagnosis in Canada.

Methods: We undertook a secondary analysis of two population-based surveys to determine if these could be used to estimate the prevalence of psychiatric or behavioural conditions among adults with intellectual disabilities in Canada.

Results: The surveys reflect prevalence estimates of intellectual disabilities (CCHS: 0.2% and PALS: 0.5%) that are considerably lower than those published in the literature. While it was possible to calculate the proportion of individuals with a dual diagnosis (CCHS: 30.6% and PALS: 44.3%), the surveys were of limited use for detailed analyses. The estimates of prevalence derived from the surveys, especially from the CCHS, were of unacceptable quality due to high sampling variability and selection bias.

Conclusion: The estimates should be interpreted with caution due to concerns regarding the representativeness of the sample with intellectual disabilities in the national surveys.

Keywords: *mental retardation, mental disorders, health surveys, health services research*

Introduction

Intellectual disabilities can be defined as life-long conditions that present before the age of 18 years that are characterized by limitations in intellectual functioning and adaptive behaviour.[1] Intellectual disabilities affect up to 3% of the population.[2] Most studies have shown that intellectual disabilities affect more males than females.[3,4] The prevalence of diagnosed intellectual disabilities increases with age among children and adolescents.[2] However, studies of prevalence among adults consistently report rates below 1%.[5] Compared to the general population, individuals with intellectual disabilities have a higher prevalence of health problems,[6,7] including a psychiatric or behavioural condition.[8] In Canada, the term "dual diagnosis," as defined by the Canadian Mental Health Association*, usually refers to an individual with both a mental illness and an intellectual disability. Research suggests that the proportion of people with intellectual disabilities who have co-morbid psychiatric or behavioural conditions ranges from 14% to 64% depending on the population studied and the diagnostic criteria used.[9-14]

Although up to 3% of Canadians may have an intellectual disability, no studies have examined the feasibility of using national health surveys to research this population. In response to this, we examined two national health surveys, Canadian Community Health Survey (CCHS) and Participation and Activity Limitation Survey (PALS), to determine if they could be used for mental health surveillance among Canadians with an intellectual disability to potentially aid service and policy planners in learning more about this population.

Methods

We conducted a secondary analysis of two population-based surveys, CCHS and PALS. The CCHS, Cycle 3.1 (2005), is a cross-sectional survey of 130 000 Canadians aged 12 years and over, representing residents of all provinces and territories.[15] A multistage stratified cluster sampling design is used in the survey. The PALS (2006) is a cross-sectional survey of 47 500 individuals[16] that has a two-phase stratified sample design. The sampling frame for the second phase comprised all people who reported activity limitations

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* http://www.ontario.cmha.ca/about_mental_health.asp?cID=7598

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on the 2006 Canadian census. A separate dataset containing demographic information about individuals who completed the census but did not indicate activity limitations was combined with the PALS dataset. For the PALS, proxy respondents were allowed when the selected respondent was not present during the duration of the survey, did not speak English or French, or could not participate in the survey due to a physical or mental condition.[16] In the CCHS, proxy respondents were not allowed for certain questions. In both the CCHS and PALS, individuals living on Indian Reserves, Canadian Forces Bases, and institutions were excluded from the sampling frame.[15,16]

Permission was obtained from Statistics Canada to use the survey master files at the Queen's University Research Data Centre. Ethical approval was obtained from the Queen's University Research Ethics Board.

Measurement of dual diagnosis

To estimate the proportion of adults with intellectual disabilities, the CCHS asked: "Do you have autism or any other developmental disorder such as Down's syndrome, Asperger's syndrome or Rett syndrome?"[17] The PALS, in turn, asked the question: "Has a doctor, psychologist or other health professional ever said that you had a developmental disability or disorder?"[18] Conditions such as Down syndrome, autism, Asperger syndrome and mental impairment due to a lack of oxygen at birth were included as examples for the PALS respondents.

To classify an individual as having a dual diagnosis, the question assessing intellectual disability was cross-tabulated with questions in the survey that assessed self-reported mental illness. In the CCHS, mental illness was defined as having one or more of the following conditions: schizophrenia; mood disorders—depression, bipolar disorder, mania or dysthymia; anxiety disorders—phobia, obsessive-compulsive disorder or panic disorder; and eating disorders—anorexia or bulimia.[17] In the PALS, mental illness was assessed by asking respondents about emotional, psychological or psychiatric conditions that had lasted or were expected to last for 6 months or more.[18] These conditions included phobias, depression, schizophrenia, and drinking/drug problems.

Measurement of demographic variables

The analysis included data regarding respondents' sex, age and province of residence. Only individuals aged 18 years or older were included. Data regarding province of residence were grouped to create five geographical areas: British Columbia and Alberta, Saskatchewan and Manitoba, Ontario, Quebec, and the Atlantic Provinces (New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador). Yukon, Northwest Territories and Nunavut were excluded due to low cell counts.

Data management

For both surveys, responses where the answer was "refusal," "don't know" or "not stated" were not included in the analysis. SPSS software version 6.0 for Sun Ray Microsystems was used to analyze the national surveys. Data with cell counts less than 5 or 10 for the CCHS or PALS, respectively, were suppressed and the estimates not released due to confidentiality. Appropriate population weights were applied to the data. In order to calculate the 95% confidence intervals (CIs) for the prevalence estimates in the CCHS, bootstrap weights and Statistics Canada's BOOTVAR macros were used for SPSS software version 14.0 (SPSS, Chicago, IL). For the PALS, bootstrap weights were used for STATA version 10.0 software (StataCorp LP, College Station, Texas).

When assessing data quality, the coefficient of variation was calculated for each estimate by dividing the standard error of the estimate by the estimate itself, in accordance with Statistics Canada data release procedures. The quality of the estimate was quantified by Statistics Canada based on the size of the coefficient of variation as a small value corresponds to smaller variability in the sample population.[15] Estimates with coefficient of variation scores between 16.5% and 33.3% should be considered with caution due to the high sampling variability. Estimates with coefficient of variation scores greater than 33.3% are not recommended for release by Statistics Canada.[15,16]

Data analysis

We calculated the proportion of individuals with an intellectual disability in the whole population. Age- and sex-specific proportions of intellectual disability by geographic region were determined. Proportions were also calculated for each overall geographical region. The percentage of individuals with an intellectual disability who have a co-morbid psychiatric or behavioural condition was also determined, along with 95% CIs.

Results

Prevalence of intellectual disabilities in Canada

Using the CCHS, Cycle 3.1 (2005), 51 655 or 0.2% (0.17%–0.26%) of the Canadian adult population is estimated to have an intellectual disability (Table 1). The estimate is higher when using the PALS (2006): 0.5% (0.43%–0.56%) representing 112 919 individuals. In the CCHS, the prevalence of intellectual disability was 0.2% for both men (0.18%–0.30%) and women (0.12%–0.25%, high sampling variability). These proportions are higher in the PALS, where 0.6% (0.47%–0.68%) of the men and 0.4% (0.34%–0.50%) of the women have an intellectual disability. When analyzed by age, the proportion of individuals with an intellectual disability is higher in the PALS as compared to the CCHS for most age groups. In the PALS, 35% of those with an intellectual disability are under 35 years of age. A significantly lower proportion of individuals in the oldest age group (65+ years old) have an intellectual disability when compared to the other age groups in the PALS.

The geographical distribution of individuals with an intellectual disability across Canada shows a similar pattern in both surveys, but the CCHS estimates tended to be of poor quality. In the PALS, the estimates in British Columbia and Alberta, Saskatchewan and Manitoba, Ontario, and the Maritime Provinces ranged from 0.5%–0.6%. Individuals residing in Quebec had the

TABLE 1
Proportion of Canadian population with an intellectual disability by sex, age and geographical area: CCHS (2005) and PALS (2006)

	CCHS		PALS	
	Number	% (95% CI)	Number	% (95% CI)
Sex				
Male	28 484	0.2 (0.18, 0.30)	63 582	0.6 (0.47, 0.68)
Female	23 171	0.2[a] (0.12, 0.25)	49 337	0.4 (0.34, 0.50)
Age, years				
18–19	—	—	6 288	0.8 (0.55, 1.00)
20–24	12 351	0.6[a] (0.32, 0.79)	13 871	0.7 (0.59, 0.82)
25–34	14 606	0.4[a] (0.20, 0.50)	19 798	0.5 (0.39, 0.65)
35–44	8 404	0.2[a] (0.10, 0.23)	21 603	0.5 (0.37, 0.57)
45–54	8 751	0.2[a] (0.09, 0.28)	25 623	0.5 (0.37, 0.72)
55–64	1 436	< 0.1[a] (0.01, 0.07)	18 858	0.6[a] (0.27, 0.85)
65+	3 145	< 0.1[a] (0.03, 0.13)	6 879	0.2[a] (0.09, 0.28)
Geographical area				
Newfoundland, Prince Edward Island, Nova Scotia and New Brunswick	4 931	0.3[a] (0.15, 0.39)	11 027	0.6 (0.56, 0.74)
Quebec	9 623	0.2[a] (0.09, 0.24)	21 962	0.4 (0.28, 0.49)
Ontario	19 377	0.2[a] (0.13, 0.28)	45 913	0.5 (0.38, 0.67)
Saskatchewan and Manitoba	4 118	0.3[a] (0.13, 0.41)	9 054	0.6 (0.51, 0.76)
British Columbia and Alberta	13 607	0.2[a] (0.15, 0.33)	24 963	0.5 (0.38, 0.56)
Total	51 655	0.2 (0.17, 0.26)	112 919	0.5 (0.43, 0.56)

Abbreviations: CCHS, Canadian Community Health Survey; CI, confidence interval; PALS, Participation and Activity Limitation Survey.

Note: Estimates are adjusted using bootstrap weights.

[a] The estimate is considered to be of poor quality due to high sampling variability.

lowest prevalence estimate (0.4%), which was statistically significant when compared to the estimates from other geographical areas.

Dual diagnosis in Canada

The CCHS estimates the proportion of adults with an intellectual disability who have a dual diagnosis to be 30.6% (95% CI: 21.1%–40.0%) representing 15 783 Canadians (Table 2). This proportion was slightly higher in the PALS at 44.3% (95% CI: 37.5%–51.1%) representing 50 053 Canadians. The remaining CCHS estimates were of poor quality with high coefficient of variation scores limiting their publication. In the PALS, the prevalence estimates of dual diagnosis were 46.9% (95% CI: 37.1%–56.7%) for men and 41.0% (95% CI: 31.5%–50.5%) for women. However, the confidence intervals were very wide, indicating poor precision. The proportion of individuals with a dual diagnosis was lower in the youngest age group (aged 18–19 years), although this was not statistically significant. In addition, the estimate was of marginal or poor quality. The remaining estimates did not differ significantly from each other. The proportion of individuals with a dual diagnosis ranged from 37% to 49% by geographical area and the estimates were not statistically significantly different from each other.

Quality of survey estimates

A substantial number of the estimates derived from the national surveys were of poor or unacceptable quality due to high sampling variability, and therefore conclusions could not be drawn from them. This was especially true for the CCHS data where only 3 of the estimates were of reportable quality, 19 were of marginal or poor quality and 6 were of unacceptable quality and could not be released. In comparison, 27 estimates from the PALS were of reportable quality with only 5 being of marginal or poor quality.

Discussion

Identifying the population with intellectual disabilities

Both the CCHS and PALS reported a prevalence of intellectual disabilities considerably lower than the reported population prevalence, especially when compared to the estimates when children are included. A recent meta-analysis of 52 studies (cohort, case control, cross-sectional studies) found the prevalence of intellectual disability to be 1.04%, with lower rates among adults (0.49%).[5] According to the CCHS, 0.2% of Canadians reported an intellectual disability, while in the PALS this prevalence estimate was 0.5%. The prevalence estimates were dissimilar due to differences in the sample populations participating in the surveys and the manner in which information was collected for the surveys. The PALS included individuals who reported activity limitations on the Canadian census, while the CCHS was based on the selected households that replied to the survey.

Additionally, the PALS could have increased the likelihood of a person with an intellectual disability being included in the survey as it allowed proxy respondents to complete the entire survey on behalf of the selected individuals. In comparison, the CCHS restricted the type of questions that could be answered by proxy respondents. The proxy respondents needed to be familiar with the challenges

TABLE 2
Proportion of adults with intellectual disabilities with a dual diagnosis by sex, age and geographical area: CCHS (2005) and PALS (2006)

	CCHS		PALS	
	Number	% (95% CI)	Number	% (95% CI)
Sex				
Male	8 594	30.2[a] (19.8, 40.5)	29 826	46.9 (37.1, 56.7)
Female	7 189	31.0[a] (15.1, 46.9)	20 227	41.0 (31.5, 50.5)
Age, years				
18–19	—	—	1 886	30.0[a] (17.2, 42.8)
20–24	—	—	5 599	40.4 (32.5, 48.3)
25–34	—	—	9 063	45.8 (33.0, 58.6)
35–44	2 626	31.3[a] (14.8, 47.7)	10 916	50.5 (40.0, 61.1)
45–54	3 936	45.0[a] (18.1, 71.9)	12 418	48.5[a] (31.2, 65.7)
55+	—	—	10 171	39.5[a] (20.5, 58.6)
Geographical area				
Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick	1 970	40.0[a] (17.8, 62.1)	4 021	36.5 (29.5, 43.5)
Quebec	—	—	10 066	45.8 (31.1, 60.6)
Ontario	4 266	22.0[a] (8.2, 35.9)	19 758	43.0 (29.3, 56.8)
Saskatchewan, Manitoba	5 914	43.5[a] (24.4, 62.5)	3 884	42.9 (32.2, 53.7)
British Columbia, Alberta			12 323	49.4 (39.8, 58.9)
Total	15 783	30.6 (21.1, 40.0)	50 053	44.3 (37.5, 51.1)

Abbreviations: CCHS, Canadian Community Health Survey; CI, confidence interval; PALS, Participation and Activity Limitation Survey.

Note: Estimates are adjusted using bootstrap weights.

[a] The estimate is considered of poor quality due to high sampling variability.

and difficulties the person faced due to the disability.[16] Overall, 12.1% of the sample over the age of 15 years completed the PALS using a proxy respondent. Close to 60% of the subjects who completed the survey by a proxy respondent cited an inability to participate due to a physical or mental condition.[16] In contrast, less than 2% of the sample in the CCHS completed the survey using a proxy respondent.[19]

The prevalence estimates presented by CCHS and PALS data are likely lower than expected due to the population frame used. Both national surveys excluded individuals living in institutions and long-term care facilities. In 2003, an estimated 20 000 individuals with intellectual disabilities resided in health-related institutions across Canada and an additional 12 000 lived in institutional facilities specifically for people with intellectual disabilities.[20] Therefore, it is likely that a large portion of the population with intellectual disabilities was ineligible to participate in the national surveys, thereby lowering the estimate of the prevalence of intellectual disabilities in Canada from such surveys.

However, both of the national surveys found that the estimates of the proportion of adults with a dual diagnosis are similar to those reported in the literature. In studies that surveyed service recipients, 28% to 31% of individuals with intellectual disabilities had a concurrent mental health problem.[21-23]

Use of national surveys for mental health surveillance

Although it was possible to determine the overall prevalence of intellectual disabilities among adults in the CCHS (0.2%) and in the PALS (0.5%), it is possible that the samples were biased because of the low prevalence of intellectual disability detected and the method of respondent selection, raising concerns about the generalizability of the estimates. The prevalence rates of intellectual disability by sex, age and geography were of poor quality from the CCHS due to high sampling variability and could not be reported. Some prevalence rates (sex and geography) could be determined from the PALS, although age comparisons, particularly in the older age groups, were also of poor quality. Both surveys were able to determine the overall prevalence of dual diagnosis but were of limited use for more detailed analyses. Of the two surveys, the best approach for estimating the prevalence of intellectual disabilities and the proportion of these individuals with a dual diagnosis was through the PALS. These estimates are of higher quality because they had lower coefficients of variation, and the survey included proxy respondents, which potentially allowed the inclusion of people with severe intellectual disabilities in the survey. The data from the CCHS were mostly of poor quality, which limits the use of this survey.

Limitations of the surveys

Individuals with intellectual disabilities may be under-represented by the national surveys as the sampling frames exclude those who lived in institutions, such as long-term care facilities and hospitals.[15,16] The sampling frame used in the PALS may cause selection bias, as individuals with activity limitations who live in the community are chosen to participate. Moreover, individuals who do not indicate having activity limitations on the census are not included in the PALS sampling frame. Therefore, individuals with a mild intellectual disability and those who are not aware of their limitations may be missed. As a result, individuals with a very mild intellectual disability or a severe or profound intellectual disability may be missed, while those with mild or moderate intellectual disability may be over-represented.

Additionally, questions used to assess intellectual disability and mental health varied across the surveys. As a result, differing populations could have been classified as having an intellectual disability and co-morbid psychiatric or behavioural conditions, hence limiting comparability across the surveys. The level of intellectual disability, which is related to the prevalence of psychopathology,[12,22,24] was not assessed in any of the surveys.

Another limitation of using the national survey data is the inability to investigate numerous factors associated with intellectual disabilities and mental health due to low cell counts and data suppression. However, the major limitation of using national survey data is the quality of the estimates that are produced as measured by the coefficient of variation. Some of the reported estimates from the national surveys were of marginal, poor or unacceptable quality due to high sampling variability, which would limit the generalizability of the results. This limited the conclusions that could have been made about the data, particularly those in the CCHS.

Strengths of the study

To the best of our knowledge, this is the first study to examine data from two national surveys—CCHS (2005) and PALS (2006)—to assess the prevalence of intellectual disabilities and dual diagnosis in Canada. The results highlight the gaps in knowledge regarding the prevalence of intellectual disabilities in Canada and the proportion of these individuals with a dual diagnosis. However, selection bias and data quality must be taken into account when applying the results to the population with intellectual disabilities. Secondly, the variables used in the survey are available and accessible for analysis and differences across future surveys can be examined. As a result, this study can be easily reproduced.

Conclusion

Psychiatric and behavioural conditions are present in about one-third of the population with intellectual disabilities, as shown by the two surveys examined. Among the surveys, the PALS presented the highest quality of data regarding the population with a dual diagnosis. It has recently been reported that the PALS will not be funded by Human Resources and Skills Development Canada in 2011, and a new strategy for monitoring people with disabilities is to replace the survey.[25,26] The collection of data on individuals with intellectual disabilities is of importance as Canada ratified the United Nations Convention on the Rights of Persons with Disabilities in 2010.[27] The new strategy should ensure that subgroups of the population with disabilities, such as individuals with intellectual disabilities, are properly identified and that their health status is validly and reliably ascertained. Proxy responses from family members or caregivers should be allowed. In addition, the new strategy should consider identifying individuals residing in institutions. Oversampling of adults whose disabilities onset in childhood will be required to ensure adequate representation in the surveys. Tools that have been validated to assess psychopathology among adults with intellectual disabilities may be considered, especially among those individuals with moderate or severe intellectual disability.

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