Patterns of mortality among adults with intellectual and developmental disabilities in Ontario

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Abstract

Objectives To determine recent mortality rates among Ontarian adults with intellectual and developmental disabilities (IDDs) and investigate changes over time in contrast to the general population. To determine the most commonly reported underlying causes of death and explore related coding practices.

Methods Using linked health administrative data, four cohorts of adults with IDD aged 25–99 living in Ontario were followed for 1 year (one cohort for each year between 2011 and 2014). Deaths (2011 to 2014) and causes of death (2011 to 2013) were identified, and age-standardized mortality rates were calculated annually. For 2013, overall and sex-specific standardized mortality ratios (SMRs) were calculated. Mortality ratios were also examined across 5-year age groups. Commonly reported causes of death were tabulated by ICD-10 chapter, differences by sex examined, and cause-specific SMRs calculated. All deaths with IDD diagnostic codes reported as underlying cause of death were identified.

Results Mortality rates among individuals with IDD have been decreasing over time; in 2014, the mortality rate was 22.6 deaths per 1000 person-years. Disparities in mortality rates relative to the general population decreased with increasing age. Men with IDD had higher mortality rates than women with IDD. The most common causes of death among individuals with IDD were cardiovascular disease, neoplasms, and diseases of the respiratory system. An IDD diagnostic code was reported as cause of death in 3.8% of cases.

Conclusions The ongoing excess mortality among Ontarians with IDD should be closely monitored by policy makers and service providers. Attention to cause of death reporting should be considered so that cause of death can be thoroughly examined.

Résumé

Objectifs Déterminer le taux de mortalité récent chez les adultes ontariens ayant une déficience intellectuelle et développementale (DID) et explorer les changements au fil du temps des disparités avec la population générale. Déterminer les causes déclarées les plus communes qui expliquent le décès et explorer les pratiques de codage connexes.

Méthodes Au moyen des données administratives sur la santé, quatre cohortes d'adultes ayant une DID âgés de 25 à 99 ans vivant en Ontario ont été suivies pendant un an (une cohorte par année entre 2011 et 2014). Les décès (2011 à 2014) et les causes des décès (2011 à 2013) ont été cernés, et le taux de mortalité normalisé selon l'âge calculé chaque année. Pour 2013, on a calculé le ratio standardisé de mortalité (RSM) selon le genre. On a également examiné le ratio de mortalité par groupe d'âge de cinq ans. Les causes de décès déclarées le plus souvent ont été totalisées selon le chapitre du CIM-10, les différences selon le genre examinées et les causes propres au RSM calculées. Tous les décès portant un code de diagnostic DID pour désigner une cause sous-jacente ont été identifiés.

Résultats Le taux de mortalité chez les personnes ayant une DID a baissé avec le temps; il était de 22,6 par 1000 années-personnes en 2014. L'écart du taux de mortalité par rapport à la population générale a baissé avec l'âge. Les hommes ayant une DID avaient un taux de mortalité supérieur à celui des femmes ayant une DID. Les causes les plus fréquentes de décès chez les

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personnes ayant une DID étaient les maladies vasculaires, les tumeurs et les maladies du système respiratoire. Un code de diagnostic de DID a été déclaré comme cause du décès dans 3,8% des cas.

Conclusions Les décideurs et fournisseurs de service doivent surveiller de près la surmortalité actuelle chez les Ontariens ayant une DID. Il faut porter plus d'attention à la déclaration de la cause du décès pour être en mesure de l'examiner en profondeur.

Keywords Mortality rate · Intellectual disability · Cause of death · Health disparities · Developmental disability

Mots-clés Taux de mortalité · Déficience intellectuelle · Cause du décès · Disparités en matière de santé · Déficience développementale

Introduction

The UK report “Death by Indifference” (Mencap 2007) raised alarm internationally regarding the quality of health care provided to persons with intellectual and developmental disabilities. According to the 2012 Canadian Survey on Disabilities, 0.6% of Canadians aged 15 to 64 have developmental disabilities (defined as a self or proxy reported diagnosis of a developmental disability/disorder, including Down syndrome, autism, Asperger syndrome, or mental impairment due to lack of oxygen at birth) (Bizier et al. 2015). Such disabilities, referred to internationally as intellectual and developmental disabilities (IDD), originate before the age of 18 and are characterized by significant limitations in both intellectual ability and adaptive functioning impacting many everyday social and practical skills (American Association on Intellectual and Developmental Disabilities 2013). Individuals with IDD have been found to have 2.5 times more health problems than the general population (van Schrojenstein Lantman-de Valk et al. 2000). They are at increased risk for mental health problems, including psychiatric and behavioural disorders, as well as increased risk for physical health problems such as diseases of the eye or ear and diseases of the musculoskeletal system (van Schrojenstein Lantman-de Valk et al. 2000). Increased risk for certain health problems can be attributed to IDD; however, others may arise due to the unique challenges in accessing quality health care for this population, or their living conditions (van Schrojenstein Lantman-de Valk et al. 2000; Ouellette-Kuntz 2005; Lauer and McCallion 2015). Understanding the unique health care needs of individuals with IDD and identifying disparities in health and in determinants of health is an important first step in providing adequate health care to this population (Evenhuis et al. 2013; Lin et al. 2013).

Mortality is a foundational measure commonly used by epidemiologists to report on the health of a population (McCarron et al. 2015). However, Canadian mortality statistics specific to the population with IDD are limited. A recent review (Ouellette-Kuntz et al. 2015) identified only three studies of mortality among persons with IDD since 1995: two from Ontario and one from Manitoba. While the Ontario studies were not comprehensive (one Ontario study was based on a

small region, another reported only on in-hospital mortality), these studies demonstrate an excess mortality in Ontarians with IDD that is more pronounced in childhood and early adulthood as well as among women. Excess mortality and greater disparities between younger age groups have similarly been reported for populations of people with IDD in other countries (Dieckmann et al. 2015; McCarron et al. 2015). The 50% survival probability for a population with IDD is reached roughly 10 years earlier than for the general population (Bittles et al. 2002). An observed sex difference, on the other hand, has not been consistently found across studies (Heslop et al. 2014; Dieckmann et al. 2015; Florio and Trollor 2015; Lauer and McCallion 2015; McCarron et al. 2015; Trollor et al. 2017).

Some of the disparities in mortality rates may be due to the complex health problems that arise in many individuals with IDD; however, this is not likely to account for all of the excess mortality (Tyrer and McGrother 2009; Lauer and McCallion 2015). Causes of death can shed light on this matter. The three most common causes of death reported among individuals with IDD in Finland, England, and Australia are cardiovascular diseases, respiratory diseases, and neoplasms (Patja et al. 2001; Hosking et al. 2016; Trollor et al. 2017). To date, no Canadian studies have comprehensively reported on causes of death among adults with IDD.

Reliable and accurate reporting is crucial to the study of cause of death. There is evidence from other jurisdictions that IDD is being inappropriately recorded as a cause of death. Cause (s) of death recorded on the death certificate is meant to report the immediate chain of events that lead to death. Tyrer and McGrother (2009) argue that although IDD may predispose an individual to certain conditions that could contribute to death, IDD itself is not a relevant cause of death and should therefore not be listed under any cause of death field (i.e., leading, immediate, underlying, other conditions contributing) on the death certificate. Despite this, research from the UK found that approximately 40% of death certificates for individuals with IDD reported an IDD (for example, Down syndrome or autism spectrum disorder) as another condition contributing to death, and 1.2% of death certificates reported an IDD as the underlying cause of death (Tyrer and McGrother 2009).

A thorough understanding of patterns in mortality among individuals with IDD can inform policy and interventions that could reduce observed disparities (Lauer and McCallion 2015). This study addresses a critical gap in health research regarding current mortality patterns among individuals with IDD living in Canada by examining yearly mortality among adults with IDD in Ontario between 2011 and 2014. The study investigated changes in mortality rates over time and current patterns of mortality by age and sex in contrast to the general population. The causes of death were also explored, and coding practices related to causes of death were scrutinized.

Methods

Four different cohorts, one for each year between 2011 and 2014, were identified. All members of the cohorts were aged 25–99 and living in Ontario as of January 1 of that year and identified as having an IDD. Cohort definition was based on a previously defined cohort (Ouellette-Kuntz and Martin 2014). Diagnoses of IDD (Lin et al. 2013) were identified by searching the Discharge Abstract Database, Same Day Surgery Database, Ontario Mental Health Reporting System, National Ambulatory Care Reporting System, Ontario Health Insurance Plan, the Chronic Care Reporting System for Long-Term Care, and the Home Care Database. Demographic variables were obtained from the Registered Persons Database while data regarding the outcomes death (available to December 31, 2014) and causes of death (available to December 31, 2013) were obtained from the Office of the Registrar General Database. All datasets were linked using unique encoded identifiers and analyzed at the Institute for Clinical Evaluative Sciences.

To examine trends in mortality over time, crude annual person-time mortality rates and age-standardized mortality rates using the 2011 Canadian population (Statistics Canada 2011) were calculated for calendar years 2011 to 2014. The most complete data were available for 2013; therefore, data for the 2013 cohort were further analyzed to establish the most recent patterns of mortality within individuals with IDD. Age-standardized mortality rates were calculated for each sex using the 2011 Canadian population. Examining for sex differences was warranted as it has been found that in Ontario, there are more males (57.4%) than females (42.7%) affected by IDD (Lunsky et al. 2013); this is in part due to the role of x-linked disorders associated with IDD (McDermott et al. 2007). Overall and sex-specific standardized mortality ratios were derived from the mortality rates in the IDD population and the corresponding mortality rates in the general Ontario population. Confidence intervals for the age-standardized rates and standardized mortality ratios were calculated using the gamma method (Fay and Feuer 1997).

Common causes of death overall and among males and females were analyzed by categorizing all underlying causes of death into their respective ICD-10 chapter and determining the frequency of causes of death in each ICD-10 chapter. Cause-specific age-standardized mortality rates and standardized mortality ratios were calculated for the three most common causes of death using the Canadian population distribution across three broad age groups (25–44, 45–64, and 65+ years). The use of broad age groups was required due to small cell counts. Frequencies of IDD diagnostic codes identified by Lin et al. (2013) being recorded as the underlying cause of death were also tabulated.

This study was reviewed for ethical compliance by the institutional review board at Sunnybrook Health Sciences Centre, Toronto, Canada and the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, Kingston, Canada.

Results

The 2011 cohort consisted of 40,279 individuals with IDD, indicating a prevalence of 0.44% among 25- to 99-year-olds in Ontario. The cohort had an average age of 47.9 years with a larger proportion of individuals being male (53.4%). Approximately 8% of individuals identified with an IDD had Down syndrome. There were 1232 deaths for the overall cohort in 2011 with an average age at death of 69.5 years. As shown in Table 1, the size of the cohort increased each year: there were more individuals aged 25 years entering the cohort than individuals exiting because of death or reaching age 100. Because of this, the average age of the cohort dropped each year as did the average age at death. In each cohort, the proportion of male individuals was slightly higher than the proportion of females and the proportion of individuals with Down syndrome was consistently around 8.0%.

The age-standardized mortality rates for adults with IDD in Ontario have decreased from 2011 to 2014 reaching a rate of 30.3 per 1000 person-years (95% CI 28.3, 32.4) in 2014 (see Table 2).

Table 3 presents crude mortality rates and mortality ratios for 5-year age groups. Mortality rates increased with increasing age, while mortality ratios decreased with increasing age; a mortality ratio of 7.4 (95% CI 4.5, 10.4) was found for those aged 25–29 compared to a mortality ratio of 1.7 (95% CI 1.3, 2.0) for those aged 90–99. Both sexes had very similar standardized mortality ratios that were significantly greater than 1, with a ratio of 3.7 for males (95% CI 3.4, 4.1) and 3.6 for females (95% CI 3.3, 3.9). However, when sex-specific mortality rates were standardized to the same population, significant sex differences were found. In 2013, mortality rates were found to be significantly higher among males with IDD compared to females with IDD with age-standardized

Table 1 Cohort characteristics—adults with IDD 25 to 99 years of age, by year

	<i>n</i> (%) or mean (SD)			
	2011 (<i>n</i> = 40,279)	2012 (<i>n</i> = 40,375)	2013 (<i>n</i> = 40,691)	2014 (<i>n</i> = 41,266)
Age	47.9 (16.0)	47.5 (15.8)	47.0 (15.7)	46.6 (15.7)
Sex—Male	21,498 (53.4%)	21,774 (53.9%)	22,172 (54.5%)	22,701 (55.0%)
Down syndrome	3242 (8.0%)	3264 (8.1%)	3275 (8.0%)	3319 (8.0%)
Deaths	1232 (3.1%)	1078 (2.7%)	974 (2.4%)	922 (2.2%)
Age at death	69.5 (16.8)	68.6 (17.2)	67.5 (16.8)	67.0 (17.1)
IDD-coded deaths	48 (3.9%)	61 (5.7%)	37 (3.8%)	Not available

rates of 37.4 per 1000 person-years for males (95% CI 33.9, 41.2) and 29.4 per 1000 person-years for females (95% CI 26.8, 32.2).

The most recent cause of death data were available for 2013. The underlying cause of death was reported on the death certificate for 972 out of 973 deaths among individuals with IDD in that year. The five most common reported causes of death in 2013 among individuals with IDD were diseases of the circulatory system (19.7%), diseases of the respiratory system (16.0%), neoplasms (11.8%), mental and behavioural disorders (9.3%), and diseases of the nervous system (8.9%). While the three most common reported causes of death in 2013 were the same for males and females, sex differences were observed when considering the fourth and fifth most common causes of death with mental and behavioural disorders and diseases of the nervous system ranking fourth and fifth for females compared to external causes and mental and behavioural disorders for males. Table 4 compares the top three most common causes of death to the general Canadian population.

Among persons with IDD, the underlying cause of death was coded as an IDD in 3.8% of all deaths between 2011 and 2013. This means that an IDD diagnostic code as defined by Lin et al. (2013) was selected as the underlying cause of death from the conditions listed on the medical certificate as cause of death as per coding rules from the World Health Organization. Down syndrome was recorded as the cause of death in more than 80% of IDD-coded causes of death.

Table 2 Annual mortality rates per 1000 person-years for Ontarians with IDD aged 25–99 years

Year	Person-years	Crude mortality rate	Age-standardized mortality rates (95% CI) ^a
2011	39,608	31.1	37.4 (35.3, 39.6)
2012	39,793	27.1	33.4 (31.3, 35.5)
2013	40,144	24.3	31.1 (29.1, 33.2)
2014	40,687	22.6	30.3 (28.3, 32.4)

^a Standardized using the 2011 Canadian population

Discussion

In 2014, the crude mortality rate among Ontarian adults with IDD was 22.6 deaths per 1000 person-years. In 2013, results yielded a standardized mortality ratio of 3.7 (95% CI 3.4, 3.9) indicating that 3.7 times more deaths occur in this population than would be expected to occur in the Ontario population aged 25–99. Sex-specific standardized mortality ratios showed that this disparity was consistent in males and females. Age-specific mortality ratios showed that disparities were more pronounced in younger age groups but remained a concern for even the oldest age group, 90+. The most common causes of death in individuals with IDD were circulatory diseases, diseases of the respiratory system, and neoplasms; this finding was consistent between sexes.

Table 3 Crude mortality rates per 1000 person-years and mortality ratios by age for Ontarians with IDD in 2013

Age group	Age-specific mortality rates		Mortality ratio
	IDD cohort	Ontario ^a	
25–29	3.7	0.5	7.4 (4.5, 10.4)
30–34	4.2	0.5	8.4 (4.6, 12.2)
35–39	5.7	0.7	8.2 (4.8, 11.5)
40–44	8.0	1.1	7.2 (4.7, 9.7)
45–49	8.6	1.8	4.8 (3.3, 6.3)
50–54	16.7	2.8	6.0 (4.6, 7.3)
55–59	30.6	4.7	6.5 (5.3, 7.7)
60–64	38.6	7.2	5.4 (4.4, 6.4)
65–69	44.1	10.7	4.1 (3.2, 5.0)
70–74	77.8	17.8	4.4 (3.5, 5.2)
75–80	110.1	28.7	3.8 (3.1, 4.6)
80–84	143.9	51.1	2.8 (2.2, 3.4)
85–90	177.6	89.7	2.0 (1.5, 2.4)
90+	309.1	187.3	1.7 (1.3, 2.0)
Standardized Mortality Ratio			3.67 (3.4, 3.9)

^a Includes adults with and without IDD; source: Statistics Canada (2017)

Table 4 Age-standardized mortality rates and standardized mortality ratios for the three most common causes of death in Canada, adults with IDD, 2013

	Age-standardized mortality rate per 1000 person-years ^a	Number of deaths	Expected number of deaths ^a	Standardized mortality ratio
Diseases of the respiratory system	5.2 (4.4, 6.1)	156	26.39	5.9 (5.0, 6.8)
Diseases of the circulatory system	6.7 (5.8, 7.7)	192	79.79	3.4 (2.1, 2.7)
Neoplasms	3.6 (2.9, 4.3)	115	94.30	1.2 (1.0, 1.4)

^a Reference is Canada 2013; source: Statistics Canada (2017)

Excess mortality in individuals with IDD and large disparities between young and old age groups is consistent with findings from studies of mortality among individuals with IDD based in other countries (Dieckmann et al. 2015; McCarron et al. 2015). However, the age-standardized mortality rate and standardized mortality ratio for our study were higher than reports from existing literature. Lauer and McCallion (2015) examined mortality in adults with IDD (aged 18+) in the US using administrative data and found an age-adjusted mortality rate of 13.6 per 1000 and a standardized mortality ratio of 1.8, both of which are roughly half of what we have found using similar methods in Ontario. This difference could in part be due to our ability to adjust using 5-year intervals to age 90+ while Lauer and McCallion were limited to using 10-year intervals to 75+.

Patterns in mortality by age are consistent with the literature: disparities are more pronounced in younger age groups. McCarron et al. (2015) found a standardized mortality ratio of about 6 for individuals aged 20–29 decreasing to 2.7 in the highest age group of 80+; similarly, Florio and Trollor (2015) found a standardized mortality ratio of 5.5 for individuals aged 25–29, decreasing to 1.7 for the highest age group, 65–69. We found a ratio of 7.4 (95% CI 4.5, 10.4) for our youngest age group (25–29) and a ratio of 1.7 (95% CI 1.3, 2.0) for our oldest age group (90+). These findings suggest that members of the IDD cohort who survive become increasingly similar to the general population with advancing age in terms of their risk of dying.

The most current age-standardized mortality rates show that males with IDD have a higher mortality rate than females with IDD. This is consistent with patterns by sex in the general population. In fact, when compared to their sex-specific counterparts in the general population, the standardized mortality ratio of males with IDD is very similar to the standardized mortality ratio of females with IDD. This indicates that while disparities exist for both sexes, the disparities were not found to be greater for either sex. In the literature, there is no consistent pattern found for mortality among sexes. Some report mortality rates higher in males than in females (Dieckmann et al. 2015; Trollor et al. 2017) while others found higher rates in females than in males (Lauer and McCallion 2015). When examining disparities in mortality across sex between

individuals with IDD and the general population, Florio and Trollor (2015) and McCarron et al. (2015) have found higher standardized mortality ratios among females with IDD, whereas Trollor et al. (2017) found no difference across sex using comparative mortality figures. Studies examining differences in mortality across sex as their primary hypothesis are warranted since the question remains unanswered.

The most common causes of death in individuals with IDD (circulatory, respiratory, neoplasms) are relatively consistent with the most common causes of death among Canadian adults. However, the standardized mortality ratios for circulatory and respiratory diseases show excess mortality due to these causes among adults with IDD. Other causes of mortality such as mental and behavioural disorders and diseases of the nervous system were reported more commonly in individuals with IDD than in the general population. Higher mortality in these diagnostic categories could be anticipated since mental health problems and neurological disorders such as epilepsy are common among those with IDD (McGrother et al. 2006).

Ontario's Medical Certificate of Death which is based on the recommendations of the World Health Organization (Office of the Registrar General 2010) records immediate cause of death and antecedent causes (if any) giving rise to the immediate cause, stating the underlying cause last. The immediate cause of death is defined as the condition that directly caused the death. Any conditions that preceded the immediate cause of death are written on the subsequent lines in reverse order on the death certificate. The underlying cause of death is the final line in this sequence and is intended to be the disease or injury which initiated the train of morbid events leading directly or indirectly to death. An IDD diagnostic code was listed as the underlying cause of death in nearly 4% of deaths among individuals with IDD. This was more than three times the proportion of IDD coded underlying cause of death found in the UK by Tyrer and McGrother (2009). Generally, it is inappropriate to list an IDD as the underlying cause of death as it does not cause death, nor does it cause other conditions leading to death, though it may predispose an individual to them. Attention should be paid to coding practices with regard to the cause of death when the decedents have IDD.

The trend analysis suggests that mortality rates in the population of Ontario adults with IDD have decreased between

2011 (31.2/1000) and 2014 (22.6/1000). It is possible that this finding is an artifact of misclassification during cohort creation. The cohort is based on case definition relying on the presence of diagnostic codes in health administrative datasets (Lin et al. 2013). It is possible that individuals with dementia or traumatic brain injuries were misclassified as having IDD. If these individuals were at a greater risk of dying, the mortality rates in the earlier years would be overestimated. As our main findings are based on a later year (2013), the effect of such misclassification is of lesser concern.

Limitations

Using health administrative databases to define our cohort meant no information on level of disability was available. This study could not examine the effect of increasing severity of IDD on mortality rates in Canada. Additionally, this study did not address the impact of level of social support, intensity of care received, co-morbidities, or living arrangements, on mortality among adults with IDD. All of these may contribute to observed excess mortality warranting future research that examines these variables and their impact on mortality among individuals with IDD.

The current study identified 0.44% of Ontarians aged 25–99 in 2011 as having an IDD. While this is lower than the prevalence reported by Bizier et al. (2015), it is not unexpected. The lower prevalence can be explained by the difference in ages being studied, the case definition, and the methods used. As Bizier et al. (2015) showed, in the Canadian Survey on Disability, the prevalence ranged from 0.4% to 0.5% among those 25 to 64 years. Furthermore, the Canadian Survey on Disability included cerebral palsy (CP) as a developmental disability whereas it was not included among the IDD codes to define the current cohort since CP can occur without cognitive impairment. Finally, the lower prevalence may also be in part due to the identification of IDD using health administrative databases as persons with milder disabilities may be less likely to have an IDD coded encounter with the healthcare system. In fact, Bizier et al. (2015) report that 15% of the individuals identified as having a developmental disability in the national survey did not report significant limitations in functioning.

Conclusion

Despite apparent decreases in mortality among adults with IDD, excess mortality remains. It becomes difficult to describe possible causes for this excess and potential interventions when true cause of death is unknown. Care should be taken with cause of death reporting so that reasons for these disparities can be further explored. In particular, there is a need to

understand the extent to which deaths among adults with IDD could be avoided either because they could be prevented by optimizing healthcare or through public health interventions. Ongoing monitoring of mortality among adults with IDD in Canada is warranted.

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Compliance with Ethics Standards

This study was reviewed for ethical compliance by the institutional review board at Sunnybrook Health Sciences Centre, Toronto, Canada and the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, Kingston, Canada.

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