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 (IDD) 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 one 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 were calculated. Mortality ratios were also examined across 5-year age groups. Commonly reported causes of death were tabulated by ICD-10 chapter, and differences by sex examined. 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 age-standardized mortality rate was 30.3 deaths per 1 000 person-years. Disparities in mortality rates relative to the general population decreased with increasing age. No significant sex differences were found. 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.

KEY WORDS

mortality rate; intellectual disability; cause of death; health disparities; developmental disability

INTRODUCTION

The UK report "Death by Indifference" (Mencap 2007) raised alarm internationally regarding the quality of healthcare 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 et al. 2000). These health problems include increased risk for mental health problems such as neurological or psychological 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 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 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 form 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). 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 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 are 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 United Kingdom 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 1st 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 [removed for blinding].

To examine trends in mortality over time, crude annual person-time mortality rates and age-standardized mortality rates were calculated for calendar years 2011 to 2014. When comparing to overall mortality rates in Ontario, it is important to report age-adjusted rates since the 50% survival probability for a population with IDD is reached roughly 10 years earlier than the general population (Bittles et al. 2002). Hence, mortality rates were age standardized using the 2011 Canadian population (Statistics Canada n.d.).

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 by sex and standardized using the 2011 Canadian male and female populations respectively. 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. 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 [removed for blinding].

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 1 232 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%.

Table 1: Cohort characteristics – Adults with IDD 25 to 99 years of age, by year

	n (%) or mean (SD)			
	2011 (n=40 279)	2012 (n=40 375)	2013 (n=40 691)	2014 (n=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	3 242 (8.0%)	3 264 (8.1%)	3 275 (8.0%)	3 319 (8.0%)
Deaths	1 232 (3.1%)	1 078 (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

The age standardized mortality rates for adults with IDD in Ontario have decreased from 2011 to 2014 reaching a rate of 30.3 per 1 000 person-years (95% C.I.: 28.3, 32.4) in 2014 (see Table 2). In 2013, mortality rates were not found to be significantly different between sexes with a rate of 31.9 per 1 000 person-years for males (95% C.I.: 29.0, 35.0) and a rate of 30.4 per 1 000 person-years for females (95% C.I.: 27.7, 33.3). To compare mortality rates within our cohort to the Ontario population, standardized mortality ratios were calculated. Both sexes had statistically significant standardized mortality ratios with a ratio of 3.7 for males (95%. C.I.: 3.4, 4.1) and 3.6 for females (95% C.I.: 3.3, 3.9), but neither significantly higher than the other. 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% C.I.: 4.5, 10.4) was found for those aged 25-29 compared to a mortality ratio of 1.7 (95% C.I.: 1.3, 2.0) for those aged 90-99.

Table 2: Annual mortality rates per 1 000 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 by age using the 2011 Canadian population

Table 3: Crude mortality rates per 1 000 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 (No date)

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 behavioral 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 behavioral disorders and diseases of the nervous system ranking fourth and fifth for females compared to external causes and mental and behavioral disorders for males. Table 4 compares the top three most common causes of death by sex to the general population.

Table 4: Most common causes of death by sex among adults with IDD in Ontario and for all of Canada (percentage of deaths in 2013)

	IDD cohort	Canada[a]
Males	Diseases of the Circulatory System (19.4%)	Neoplasms (32.2%)
	Diseases of the Respiratory System (18.2%)	Diseases of the Circulatory System (24.9%)
	Neoplasms (10.9%)	Diseases of the Respiratory System (9.3%)
Females	Diseases of the Circulatory System (20.0%)	Neoplasms (29.4%)
	Diseases of the Respiratory System (13.8%)	Diseases of the Circulatory System (27.5%)
	Neoplasms (12.7%)	Diseases of the Respiratory System (9.3%)

[a]Includes adults with and without IDD; source: Statistics Canada (No date)

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 recorded on the death certificate in the underlying cause of death field. Down syndrome was recorded as the cause of death in more than 80% of IDD-coded causes of death.

DISCUSSION

Between 2011 and 2014, mortality rates in the population of Ontarian adults with IDD have decreased, with the most recent results showing an age-standardized mortality rate of 30.3 deaths per 1 000 person-years (95% C.I.: 28.3, 32.4). In 2013, results yielded a standardized mortality ratio of 3.7 (95% C.I.: 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.

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 United States using administrative data and found an age-adjusted mortality rate of 13.6 per thousand and a standardized mortality ratio of 1.8 and, 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% C.I.: 4.5,10.4) for our youngest age group, (25-29) and a ratio of 1.7 (95% C.I.: 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.

The most current age standardized mortality rates and standardized mortality ratios show no significant differences in mortality between males and females with IDD in Ontario. 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 gender 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, these most common causes of death only account for 47.5% of deaths among adults

with IDD compared to 66.2% in the general population. Other causes of mortality such as mental and behavioral 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 neural disorders such as epilepsy are common among those with IDD (McGrother et al. 2006).

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 3 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 on the death certificate 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 regards to the cause of death when the decedents have IDD.

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; such surveillance should include reporting on rates of avoidable mortality.

REFERENCES

American Association on Intellectual and Developmental Disabilities. (2013). Definition of Intellectual Disability. http://www.aaidd.org/intellectualdisability/definition#.WR3yMk2GO71. Accessed 18 May 2017.

Bittles, A.H., Petterson, B.A., Sullivan, S.G., Hussain, R., Glasson, E.J. & Montgomery, P.D. (2002). The influence of intellectual disability on life expectancy. *The Journals of Gerontology: Series A*, 57(7), M470-M472.

Bizier, C., Fawcett, G., Gilbert, S. & Marshall, C. (2015). Developmental disabilities among Canadians aged 15 years an older, 2012. Statistics Canada Catalogue no. 89-654-X2015003.

Dieckmann, F., Giovis, C., & Offergeld, J. (2015). The life expectancy of people with intellectual disabilities in Germany. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 373-382.

Evenhuis, H., Schoufour, J., & Echteld, M. (2013). Frailty and intellectual disability: A different operationalization?. *Developmental Disabilities Research Reviews*, 18(1), 17-21.

Fay, M. P., & Feuer, E. J. (1997). Confidence intervals for directly standardized rates: a method based on the gamma distribution. *Statistics in Medicine*, 16(7), 791-801.

Florio, T., & Trollor, J. (2015). Mortality among a cohort of persons with an intellectual disability in New South Wales, Australia. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 383-393.

Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*, 383(9920), 889-895.

Hosking, F. J., Carey, I. M., Shah, S. M., Harris, T., DeWilde, S., Beighton, C., & Cook, D. G. (2016). Mortality among adults with intellectual disability in England: comparisons with the general population. *American Journal of Public Health*, 106(8), 1483-1490.

Lauer, E., & McCallion, P. (2015). Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 394-405.

Lin, E., Balogh, R., Cobigo, V., Ouellette-Kuntz, H., Wilton, A. S., & Lunsky, Y. (2013). Using administrative health data to identify individuals with intellectual and developmental disabilities: a comparison of algorithms. *Journal of Intellectual Disability Research*, 57(5), 462-477.

Lunsky, Y., Klein-Geltink, J.E., & Yates, E.A. (2013). Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario. Toronto, ON: Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health.

McCarron, M., Carroll, R., Kelly, C., & McCallion, P. (2015). Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 406-413.

McDermott, S., Durkin, M. S., Schupf, N., & Stein, Z. A. (2007). Epidemiology and etiology of mental retardation. In *Handbook of intellectual and developmental disabilities* (pp. 3-40). New York: Springer.

McGrother, C. W., Bhaumik, S., Thorp, C. F., Hauck, A., Branford, D., & Watson, J. M. (2006). Epilepsy in adults with intellectual disabilities: prevalence, associations and service implications. *Seizure*, 15(6), 376-386.

Mencap (2007). Death by Indifference. https://www.mencap.org.uk/death-by-indifference. Accessed 1 May 2017.

Ouellette-Kuntz, H. (2005). Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 18(2), 113-121.

Ouellette-Kuntz, H., Shooshtari, S., Balogh, R., & Martens, P. (2015). Understanding information about mortality among people with intellectual and developmental disabilities in Canada. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 423-435.

Ouellette-Kuntz, H., & Martin, L. (2014). Applied Health Research Question Report: Aging profiles of adults with and without developmental disabilities in Ontario. Toronto, ON: Health Care Access Research and Developmental Disabilities Program.

Patja, K., Molsa, P., & Iivanainen, M. (2001). Cause-specific mortality of people with intellectual disability in a population based, 35-year follow-up study. *Journal of Intellectual Disability Research*, 45(1), 30-40.

Statistics Canada. 2011. *2011 Census of Population*. Statistics Canada Catalogue no. 98-311-XCB2011018. Ottawa. Version updated February 14 2017.

Statistics Canada. No date. CANSIM (database). Last updated 22 September 2017. http://www5.statcan.gc.ca/cansim/home-accueil?lang=eng. Accessed 25 September 2017.

Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open*, 7(2), e013489.

Tyrer, F., & McGrother, C. (2009). Cause specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of Intellectual Disability Research*, 53(11), 898-904.

van Schrojenstein Lantman-De Valk, H.M., Metsemakers, J.F., Haveman, M.J., & Crebolder, H.F. (2000). Health problems in people with intellectual disability in general practice: a comparative study. *Family Practice*, 17(5), 405-407.