

Changing Trends in Life Expectancy in Intellectual Disability over Time

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Abstract

Decreased life expectancy (LE) has historically been found among people with intellectual disability (ID) compared to the general population. Several recent studies have looked into ageing and cause of death in ID. Results of many of these studies suggest that, although LE in ID remains lower than the general population, it has increased across many Western societies in recent decades. Increases in LE in the general and ID populations appear to follow similar trends. Some major causes of mortality in ID are similar to the general population, and therefore may be amenable to similar preventative healthcare interventions. In this article, we have outlined possible reasons for improved LE in ID, and potential areas that may require further intervention. However, more detailed studies on mortality in ID may provide more accurate insight into areas requiring intervention in ID populations.

Introduction

Recent studies indicate that life expectancy (LE) in people with intellectual disability (ID) has increased across almost all Western societies in recent decades, although this remains substantially lower than LE in the general population¹. Historically, higher mortality rates and decreased LE have been found among people with ID compared to the general population, translating to estimates of increased risk of death ranging between 3-18 times higher than the general population².

Globally, 0.3-0.5% of children are reported to have severe ID, and 0.2-0.4% are reported to have mild ID³. In Ireland, the greatest proportion of respondents (38%) to the ID Supplement of The Irish Longitudinal Study on Ageing (IDS-TILDA) had moderate ID⁴. There are many factors associated with increased mortality rates in people with ID, with many suffering from obesity, ischaemic and non-ischaemic heart disease, epilepsy, dementia and psychiatric problems³. Glover et al.'s findings suggest that circulatory, respiratory and neoplastic diseases were the most common causes of death in their cohort⁵. Concern has been expressed about preventable deaths in people with ID, and therefore several studies in recent years have looked into ageing experiences and mortality in the ID population.

Trends in life expectancy in people with intellectual disability compared with the general population

Several papers report that increases in LE in the general population and people with ID follow similar trends^{3,6}. Coppus found the exception to this trend applied to severe and multiple disabilities or Down Syndrome⁷. Estimates from the UK and USA show significant improvements in LE in people with ID, with increases in LE in mild ID being similar to trends in the general population^{1,3}.

Average LE across the developed world is approximately 80 years of age. Irish statistics report average LE in females to be 82.8 years, and 78.4 years for males⁸. Glover et al. report average LE for the general population in England to

be 85.3 years⁵. This same study reported the average LE in people with ID in England as 65.5, representing over 19 years difference in age at mortality⁵. Similarly, McCarron et al. reported findings that on average, the Irish ID population die approximately 19 years earlier than the general Irish population⁴. In comparison, in data from England and Wales, Heslop et al. found that age at death of males with ID was 65 years and 63 years in females with ID, 13 and 20 years younger than their sex-matched counterparts in the general population, respectively⁹. Kiani et al. also report that the average age at mortality of those with ID was up to 16 years lower than the general population in Leicestershire¹⁰. They hypothesised that modifiable poor care and service provision may contribute to this mortality gap¹⁰.

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) study, 2013, found the median age at death for people with ID in the UK to be 64 years¹¹. However, significant disparities were noted when comparing median age at death between levels of disability. The median age at death for those with profound ID was 46, severe ID was 59, moderate ID was 65 and mild ID was 67.5, indicating a step-wise decline in LE with increasing severity of ID¹¹. Even in mild ID, this still represents a markedly lower LE than the general population, whose median age at death is 80.5. For those with ID, 22% of the population were under the age of 50 at death, compared with 9% in the general population¹¹.

In a 33-year longitudinal study into trends in LE in the ID population in Sheffield, estimates of LE tended to fluctuate between 61-78% of that of the general population¹². Over the 33-year period, average LE in the general population increased from 74 years to 81 years, compared to an increase from 51 years to approximately 60 years in the corresponding ID population¹². Bittles et al. found that, in a cohort sample in Western Australia between 1953 and 2000, median age at death in people with ID increased from 9.6 to 44.6 years, likely indicating improvements in paediatric care, and that the 50% survival probability in the ID population was 68.6 years, compared to 75.6 years in the general population³. A summary of median LE across studies is presented in Table 1.

Encouragingly, evidence from several studies suggests that there have been positive developments in care for people with ID, with corresponding increases in LE. IDS-TILDA found that, like the general population, the largest proportion of their respondents with ID now fall within the 50-64 age bracket⁴. A number of studies also mentioned that trends in increasing LE of people with mild ID appears to be almost equal to that of the general population^{1,3,7}.

Table 1: Comparison of life expectancy trends across literature.

<i>Decade</i>	<i>Median age at death</i>								
1930	9								
1950	12	9.6							
1960	18	12.4							
1970	30	15.7							
1980	35	20.7					51		
1990	56	27.5		56					
2000	60	44.6	66.7	66					
2010			65.5	59	60	64	60	54	69.7
<i>References</i>	13	3	5	4	10	11	12	14	15

Causes of mortality in the ID population

Many studies have focused on mortality rates and common causes of death in people with ID. Glover et al. reported that the standardised mortality ratio (SMR) in the ID population when compared to the general population was 3.18, with life expectancy being 19.7 years lower⁵. These values varied between studies. Kiani et al. and Uppal et al. reported a SMR value of 2^{10,6}, while Hosking et al. reported the death rate in those with ID to be 5 times higher than the general population². IDS-TILDA cited a SMR 4 times higher than the general population in Ireland⁴. Similar to the CIPOLD study, findings from IDS-TILDA also showed that death occurred earlier in more severe ID than in mild or moderate ID⁴.

Several studies referenced the tendency of people with ID towards obesity, cardiac issues, epilepsy, cancer and dementia^{2,5,9}. Other factors also contributed to morbidity and mortality in people with ID, such as osteoporosis,

arthritis, falls, urinary incontinence and constipation⁴. Younger adults with ID tended to have higher incidences of risk factors for cardiovascular disease than same age and older cohorts in the general population⁹.

The combination of ID and epilepsy was found to be a risk factor for premature death compared to those with epilepsy who do not have ID and those with ID who do not have epilepsy¹⁰. Several studies reference epilepsy as a risk factor for increased mortality and reduced LE across all levels of ID^{1,9}. Epilepsy was identified as a risk factor for in-hospital mortality in the Down's Syndrome population following multivariate analysis⁶, and accounts for 3.9% more avoidable deaths in people with ID when compared to the general population².

Kiani et al.'s study of epilepsy-related mortality in ID was significant in demonstrating the disparity in risk of premature death related to sudden unexplained death in epilepsy (SUDEP) when comparing death certificates in the ID and general populations with epilepsy, over an 18-year period in Leicestershire. Of 898 people with ID who died within this period, 244 had a diagnosis of epilepsy (27%) compared with 0.5-1% cited as the average epilepsy prevalence in the general population. Of these 244 deaths related to epilepsy in ID patients, 26 people (10.6%) were due to probable/definite SUDEP. In comparison, in the population of patients with epilepsy but without ID (607 patients), 83 deaths were related to SUDEP (13.7%). The prevalence of epilepsy in ID patients is significantly higher than in the general population, making the number of SUDEP-related deaths in the ID substantial in this cohort¹⁰. Risk factors for SUDEP are also significantly more common in ID populations, such as early epilepsy onset, structural brain abnormality, accompanying psychotropic medications, IQ <70, poor medication understanding/adherence¹⁰. Of note, Kiani et al. reported poor documentation as being a limiting factor in their study, mentioning poor detail surrounding exact circumstances on death certificates in epilepsy¹⁰.

Discussion

The findings of this literature review indicate that, despite improvements in LE in people with ID, there still remains a marked gap in age of mortality between the ID population and the general population, with the size of the discrepancy in LE relatively unchanged. More than one-third of these deaths are potentially amenable to healthcare intervention². With an ageing ID population, conditions causing morbidity and mortality in ID will require development of preventative healthcare interventions specifically targeted to these populations. For example, several studies reference the tendency of the ID population towards obesity, cardiovascular and respiratory diseases^{2,5,9}, suggesting there may be a requirement for lifestyle education tailored to this cohort.

One of the most striking causes of potentially preventable mortality in the ID population is SUDEP, given the higher prevalence of epilepsy in the ID population. This is another cause of mortality that could be amenable to healthcare intervention, by educating patients or their carers about medication compliance and acute seizure management out of hospital, and limiting polypharmacy with psychotropic medications in this cohort, where possible.

Several papers cited the issue of underreporting of ID in patients, both in medical records and death certificates^{2,6,10}. Lack of reliable information is an important barrier to developing healthcare strategies targeting the ID population. Due to incomplete recording of ID on death certificates, studies based on death certificates alone may not be representative of mortality statistics and experiences in the ID population². Inconsistent reporting can lead to incorrect data about morbidity and mortality in the ID population, therefore affecting research and efforts to reduce healthcare inequities in people with ID³.

Declaration Conflicts of Interest:

The author has no conflicts of interest to declare.

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References:

1. Patja K, Molsa P and Iivanainen M. (2001) Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *J Intellect Disabil Res* 45: 30-40.
2. Hosking FJ, Carey IM, Shah SM, Harris T, DeWilde S, Beighton C and Cook DG (2016) Mortality Among Adults With Intellectual Disability in England: Comparisons With the General Population. *Am J Public Health* 106: 1483-1490.
3. Bittles AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ and Montgomery PD (2002) The influence of intellectual disability on life expectancy. *J Gerontol A Biol Sci Med Sci* 57(7):M470-2
4. McCarron M, Carroll R, Kelly C and McCallion P. (2015) Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012. *J Appl Res Intellect Disabil* 28: 406-413.
5. Glover G, Williams R, Heslop P, Oyinlola J and Grey J. (2017) Mortality in people with intellectual disabilities in England. *J Intellect Disabil Res* 61: 62-74.
6. Uppal H, Chandran S and Potluri R. (2015) Risk factors for mortality in Down syndrome. *J Intellect Disabil Res* 59: 873-881.
7. Coppus AM. (2013) People with intellectual disability: what do we know about adulthood and life expectancy? *Dev Disabil Res Rev* 18: 6-16.
8. Central Statistics Office. (2015) Irish Life Tables 2010-2012. 2018.
9. Heslop P and Glover G. (2015) Mortality of People with Intellectual Disabilities in England: A Comparison of Data from Existing Sources. *J Appl Res Intellect Disabil* 28: 414-422.
10. Kiani R, Tyrer F, Jesu A, Bhaumik S, Gangavati S, Walker G, Kazmi S and Barrett M. (2014) Mortality from sudden unexpected death in epilepsy (SUDEP) in a cohort of adults with intellectual disability. *J Intellect Disabil Res* 58: 508-520.
11. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A and Russ L. (2014) The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 383: 889-895.
12. Emerson E. GG, Hatton C. and Wolstenholme J. (2016) Trends in age-standardised mortality rates and life expectancy of people with learning disabilities in Sheffield over a 33-year period. *Tizard Learning Disability Review* 19: 90-95.
13. Bittles AH and Glasson EJ. (2004) Clinical, social, and ethical implications of changing life expectancy in Down syndrome. *Dev Med Child Neurol* 46: 282-286.
14. Trollor J, Srasuebku P, Xu H and Howlett S. (2017) Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open* 7: e013489.
15. Dieckmann F, Giovis C and Offergeld J. (2015) The Life Expectancy of People with Intellectual Disabilities in Germany. *J Appl Res Intellect Disabil* 28: 373-382.