

Executive Summary: Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down syndrome

Key findings:

- Adults with learning disabilities are twice as likely to die from preventable illness
- Premature death was 5 times higher for people with Down Syndrome
- Common causes of death were from treatable conditions including pneumonia, other respiratory conditions and epilepsy

Context:

Studies have shown that people with intellectual disabilities die at a younger age than other people; on average, 20 years younger, or 28 years younger specifically for people with Down syndrome. It has been demonstrated that people with intellectual disabilities receive poorer management of their long-term conditions within primary healthcare services compared with the general population, and which is likely to contribute to earlier mortality. Most recent studies have not split adults with, from those without Down syndrome. Most studies have not studied risk factors for death and the existing data on causes of death varies.

The purpose of this study was to find out the rates, causes, place, and risk factors for mortality in adults with learning disabilities in community settings. By increasing our knowledge and understanding of these factors, this may provide a pathway to action to reduce premature deaths among this population.

This study identified 961 adults (16-83 years; mean=44.1 years; 54.6% male) with intellectual disabilities in the Greater Glasgow area, who were clinically examined in 2001-2004 and their clinical data was linked to death registrations in 2018.

Findings

Over 15 years, 294 out of 961 (30.6%) adults with learning disabilities died. 64 out of 179 (35.8%) adults with Down syndrome died. 230 out of 783 (29.4%) adults without Down syndrome died. Deaths were more than five times as common for the adults with Down syndrome, compared with the general population. Deaths were almost twice as common for the adults without Down syndrome. The study found that aspiration/reflux/choking is the most common underlying cause of death in adults with intellectual disabilities, followed by respiratory infection. However, many types of causes of death were *more* common among this group than in the general population. For the adults with Down syndrome, the most common causes of death were dementia, then infections. For the adults without Down syndrome, the most common causes of death were breathing food or liquid into airways when trying to swallow or breathing in vomit during heartburn/choking, and lung infections.

29.8% of all the deaths were found to be preventable with appropriate care. This is more than twice as common compared with the rest of the population. 60.3% of the identified group died in hospital.

Other causes of death among this group include adults who were tube-fed, increased age, smoking, and who had Down syndrome, diabetes, lung infections, epilepsy, hearing problems, and those who were prescribed multiple medications.

Conclusions

Adults with learning disabilities with and without Down syndrome have different rates and causes of death. It is important that these are recorded separately, as adults with Down syndrome form a notable proportion of all adults with intellectual disabilities (19% in this cohort), and because they have a different pattern of clinical conditions compared with other adults with intellectual disabilities.

Both die younger, from different causes than the general population. Some mortality risk factors are the same as the general population, with earlier mortality due to co-morbidities. Among the population with intellectual disabilities, many deaths are due to conditions which could have been treated or prevented with the appropriate care.

Implications for policy and practice

These findings should inform clinical care, health policy and guidance in order to reduce early deaths. It is recommended that health care staff undertake specific training to detect and avoid problems with aspiration, swallowing and choking for people with intellectual disabilities. By raising awareness of its consequences (death) and putting in place training on simple measures related to feeding, positioning, food consistency, and when to involve speech and language therapy, physiotherapy, nursing, and medical advice, this can reduce risk of premature mortality.

Furthermore, we recommend training for clinical staff and healthcare workers to identify and manage pain, particularly conditions such as gastrointestinal ulcers and treatable conditions such as constipation and urinary tract infections so that these are managed before they lead to respiratory distress and sepsis and are therefore less likely to respond to treatment.

It is also strongly recommended that training and guidance around reasonable adjustments to improve health care be implemented to improve outcomes for people with intellectual disabilities.

This work was led by Professor Sally-Ann Cooper. The full article can be found online at <https://bmjopen.bmj.com/content/10/5/e036465>

The Scottish Learning Disabilities Observatory is funded by the Scottish Government to generate evidence and build understanding of the causes of poor health and health inequalities experienced by people with learning disabilities and people with autism. If you would like more information about this or any of our work, please contact us via slido-info@glasgow.ac.uk