Scottish Learning Disabilities Observatory

University of Glasgow

Respiratory-associated deaths in people with learning/intellectual disabilities

Key points

- People with learning/intellectual disabilities are up to 11 times more likely to die from respiratory illness compared with the general population
- The risk of death from pneumonia is 27 times higher for people with learning/intellectual disabilities
- Many respiratory deaths among the population with learning/intellectual disabilities are avoidable

Why is this study important?

People with learning/intellectual disabilities die up to 20 years earlier than the general population, often from avoidable causes. Respiratory disorders are a leading cause of death among people with learning/intellectual disabilities including preventable and treatable conditions such as pneumonia and aspiration, for example due to swallowing problems.

Studies have reported higher rates of asthma, chronic obstructive pulmonary disease and upper respiratory tract infections for people with learning/intellectual disabilities. People with profound and multiple learning/intellectual disabilities are particularly at risk of infections including sepsis and pneumonia and are more likely to have gastro-oesophageal reflux disease. Problems with swallowing are also common in those with severe learning/intellectual disabilities and can lead to chest infections.

Respiratory disease has been reported to be one of the most common causes of death in children and young people with learning/intellectual disabilities. However, there are significant gaps in the research on respiratory related mortality in the population with learning/intellectual disabilities.

How was this study developed?

This study reviewed and analysed the available evidence concerning respiratory deaths among people with learning/intellectual disabilities over the past 35 years. This approach allowed us to investigate the deaths of 1,844 people with learning/intellectual disabilities from included studies.

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Main results

This is the first study to have applied meta-analysis to respiratory mortality for the population with learning/intellectual disabilities compared with the general population. Our findings provide conclusive and robust evidence that people with learning/intellectual disabilities have a higher risk of dying from respiratory conditions.

Pneumonia and other respiratory infections are the main cause of respiratory related deaths in people with learning/intellectual disabilities.

The majority of respiratory related deaths in people with learning/intellectual disabilities are avoidable if people with learning/intellectual disabilities have equitable access to public health interventions and effective health care.

Programmes to improve the prevention, recognition and management of respiratory conditions should be implemented to reduce the inequalities in mortality experienced by people with learning/intellectual disabilities, across the lifespan.

Recommendations for policy and practice

Respiratory conditions are a major cause of premature death in the population with learning/intellectual disabilities. To address this, action is required from policymakers and practitioners across health and social care. We recommend:

- Routine monitoring and reporting of respiratory deaths in the population with learning/intellectual disabilities
- Implementation of preventative action. This should include increasing awareness and training on the link between swallowing problems and pneumonia among carers and clinicians
- Increase uptake of flu vaccinations for people with learning/intellectual disabilities and other targeted infection control measures
- Community-and hospital-based sepsis management programmes should have a lower threshold for investigating and treating pneumonia and other respiratory infections in people with learning/intellectual disabilities

Understanding the risk factors for respiratory associated deaths has important implications for disease management and the development of preventative strategies as well as for policy and practice to reduce premature deaths from respiratory-associated conditions. While this study has quantified the extent of inequalities in respiratory deaths for people with learning/intellectual disabilities more research is needed to identify the factors that lead to this increased risk.

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Next steps

This research has highlighted an urgent need for greater understanding of the specific risk factors that lead to increased risk of severe illness and death from respiratory conditions for people with learning/intellectual disabilities. The Scottish Learning Disabilities Observatory (SLDO) will undertake further research and work together with healthcare professionals in clinical practice and across specialties to highlight concern over amenable conditions such as respiratory illness, epilepsy and cerebral palsy and to identify routes to reducing premature mortality from these conditions.

The SLDO will continue to work collaboratively with the Scottish Government's Learning Disability Policy team and policy makers across health and social care to highlight the health and care needs of people with learning/intellectual disabilities.

The SLDO will also work collaboratively with social care providers, families and people with learning/intellectual disabilities, to improve understanding of risk factors, and to increase early detection of health issues.

For more information about this work, please visit – http://sldo.ac.uk/our-research/life-expectancy-and-mortality/respiratory-mortality/ or contact us via email to sldo-info@glasgow.ac.uk