



RESEARCH

INFORMATION

The relationship between autism and mortality in the Scottish population: Data linkage study of administrative and health records



AIMS

We investigated the relationship between autism and two mortality types: all-cause and avoidable mortality, which includes preventable and treatable mortality. Furthermore, we aimed to investigate several mortality risk factors, including co-occurring mental health conditions, contacts with healthcare services, and socioeconomic factors. The study used a whole population matched cohort design and included two groups of autistic people with and without co-occurring intellectual disability and a comparison group without autism or intellectual disability.



KEY FINDINGS

- Being autistic and having co-occurring intellectual disability significantly increased the risk of all-cause and treatable mortality (a type of avoidable mortality), even after controlling for the presence of mental health conditions, contact with healthcare services, and socioeconomic factors.
- More autistic young people aged 17 and under with co-occurring intellectual disability (4.3%) than autistic young people without intellectual disability (0.6%) died during the ten-year follow-



up period. Similarly, more autistic adults aged 18 and over with intellectual disability (14.4%) than autistic adults without intellectual disability (6.4%) died during the study period.

- The risk of all-cause mortality was 80% greater for autistic young people aged 17 and under than non-autistic youth, and 56% greater for autistic adults aged 18 and over than non-autistic adults. When comparing within the autistic group, the risk of all-cause mortality was 730% greater for autistic young people with co-occurring intellectual disability than autistic young people without intellectual disability, and 62% greater for autistic adults with intellectual disability than autistic adults without intellectual disability.
- Treatable mortality presented the highest mortality risk for autistic young people and adults, as there was a 246% risk increase for autistic young people compared to non-autistic young people, 555% risk increase for autistic young people with co-occurring intellectual disability compared to autistic young people without intellectual disability, 88% risk increase for autistic adults compared to non-autistic adults, and 123% risk increase for autistic adults with intellectual disability compared to autistic adults without intellectual disability.



WHAT DID THE STUDY INVOLVE?

We conducted a retrospective data linkage study to assess the relationship between autism and all-cause, avoidable, preventable, treatable, and suicide mortality in the Scottish population. All datasets were linked using Community Health Index (CHI) number by the Electronic Data Research and Innovation Service (eDRIS), done independently from the authors, and accessed via the National Safe Haven, a highly secure, controlled digital environment for analysing public sector data. We linked Scotland's Census 2011 to eight health and administrative datasets. We included any individuals over the age of 3 who were identified as autistic (n=27,725) through Scotland's Census 2011 on 27 March 2011, and matched this group by age, sex, and deprivation decile at an individual level to 276,887 non-autistic individuals without intellectual disability (1:10 ratio). We investigated deaths that occurred during the follow-up period of ten years (27 March 2011-2021).





WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

The present results showed that autism remained a risk factor for all-cause mortality and treatable mortality (a type of avoidable mortality) even after controlling for the presence of mental health conditions, contact with healthcare services, and socioeconomic factors. The fact that autism remains a risk factor for avoidable mortality despite autistic people having more frequent contact with healthcare services, and thereby there being more opportunities for intervention, suggests that autistic people are not receiving adequate health interventions in a timely manner.



WHAT IMPACT COULD THE FINDINGS HAVE?

Our study provides robust, large-scale evidence on the risk of premature mortality experienced by autistic people in Scotland. Findings from this project have been shared with the representatives of the Scottish Government's Mental Health Directorate team as well as the Scottish Parliament's Cross-Party Group on Disability to discuss policy and practice pathways towards health and healthcare improvement for autistic people in Scotland.



HOW WILL THE OUTCOMES BE DISSEMINATED?

We prepared two manuscripts for publication in academic journals and are in the process of submitting these manuscripts for peer-review. In collaboration with our third sector partners, Autistica and Edinburgh and Lothian Asperger Society, we will also organise workshops to discuss findings with people with lived experience of autism, practitioners, policy makers and commissioners. In addition, we will disseminate findings via our third sector partners' websites, newsletters and social media channels.



CONCLUSION

Our study aimed to investigate the relationship between autism and various mortality types. Our findings suggest that being autistic is a risk factor for mortality, even after accounting for the presence of mental health conditions, contact with healthcare services, and socioeconomic factors. We also showed that being autistic and having a co-occurring intellectual disability significantly increased the risk of mortality even further, highlighting the need to tailor healthcare services to meet the needs of autistic people, especially those with co-occurring intellectual disability, in all age groups.



RESEARCH TEAM & CONTACT



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Additional Information

The project was completed in October 2025.

